PUTTING PEOPLE FIRST

Mental Health and Development in South India

BasicNeeds India Initiative (Supported by Big Lottery Fund, UK)

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For CLIC - CPHE section

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Foreword

In the last decade, immense progress has been made in measuring the impact of mental illness globally. The results have been eye-opening, demonstrating that mental illness occupies a far greater proportion of the disease burden in these countries than previously expected. According to the WHO Global Programme on Evidence for Health Policy Worldwide, neuro-psychiatric illness account for 19% of disease burden, meaning 19% of all disability and death. There is a commonly held view that very poor people do not suffer from mental illness. This view is founded on the assumption that somehow mental illness are generally a disease of affluence and that poor people would not have time to be depressed. In fact of course people living in severe poverty are not protected from the plight of mental illness. To the contrary, joblessness, vulnerability to natural disaster, lack of education and physical ill-health, all markers of poverty, contribute to mental illness.

At BasicNeeds we believe in the potential of people with mental illness, in their capacity to manage their own affairs. We believe they have an important stake in development and a right to be consulted. With treatment, training and a thrust towards economic renewal, people with mental illnesses can be back in the center of things, with a dignified place in a world that once marginalised them.

It is with this idea in mind that we founded BasicNeeds in 1999. Bangalore, India, was where we set up the first country office of BasicNeeds. For my good friend D.M. Naidu and I it was a momentous time. Naidu was the first Programme Manager, BasicNeeds, and later the first Secretary of BasicNeeds India With over 10 million people with severe mental illness, poor and mostly rural, and limited professional resources, India faces a huge challenge. Any effort of ours, however small, could make a difference, we felt.

We engaged intensively with people with mental illnesses. Right from the beginning we put them in the forefront, working with them, not for them. Our principle has always been that access to good mental health is a right, not a privilege. I remember vividly the elderly Shivanna who, at an early field consultation in Ananthpur, sang of 'hope,' 'love' and the 'connectedness' of all things in the universe. It was inspiring work. The momentum grew. Our fledgling organisation had begun its journey, its model of Mental Health and Development evolving, as D.M. Naidu piloted the ideas that went into its making in South India.

There was a time when we were working with just over 100 people with mental illnesses and their carers. Today, it is with humility and satisfaction I note that in seven countries we have reached 54,076 people with mental illnesses, of whom 6448 are from South India. I wish the BasicNeeds India team, and the South India Alliance they have now formed, all success.

Chris Underhill,
Founder Director, BasicNeeds

Introduction

BasicNeeds was founded in 1999 by Chris Underhill. BasicNeeds aims at bringing change to the lives of persons with mental illness from that of neglect, to one of rights and dignity. BasicNeeds' first programme started in Bangalore in India. Now, seven years later, there are programmes in India, Sri Lanka, Ghana, Tanzania, Kenya, Uganda, Laos PDR and Columbia.

Putting People First: Mental Health and Development in South India chronicles BasicNeeds' work in South India and its impact. Taking themes that underpin the model of Mental Health and Development, it captures seven years of programme implementation. Not a vast swathe of time for an organisation, but BasicNeeds India has grown in reach and now works in the states of Karnataka, Andhra Pradesh, Tamil Nadu, Kerala, Bihar and Jharkhand.

All of this comes together in this book. It begins with cameos of Balu, Rajeshwari and Shivamma, which speak of humanity. Facts and figures are woven in - the data on which to build.

The starting years deals with the starting years of BasicNeeds, how ideas came together and the concept developed, exploring the theoretical underpinnings of the model. *Accessing Quality Treatment and Care* offers insight into the operation of the South India programme with experiential narratives, like a day at a mental health camp, with italicised write-ups focussing on people with mental illness and highlighting points of interest,

Ensuring Dignity Through Livelihoods is about livelihoods and mental health and the South India programme's initiatives in this area. *Spreading and Scaling up* is devoted to the catalytic development of the South India Alliance in 2007, and *Creating Change* through advocacy and policy work. Management and administration constitutes the chapter on *Holding the Model in Place*.

Finally, in *Looking Back, Moving Forward*, the strengths of the South India programme unfold against the challenges it faces. There is unfinished work still, and BasicNeeds India is aware that "this is only a start."

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Acknowledgments

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Special thanks to the BasicNeeds India team and partner organisations for their valuable insights into the South India Programme. Our heartfelt gratitude to people with mental illness who are at the center of our work.

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Understanding the Issue, and the People

"I have not conceived my mission to be that of a knight errant wandering everywhere to deliver people from difficult situations. My humble occupation has been to show people how they can solve their own difficulties."

– M.K.Gandhi

Balu was found wandering in a disoriented state in Talwadi village in Tamil Nadu by the field staff of TREAD, Partner organisation of Vidya Sagar. Dr. Anbudurai, a local psychiatrist, diagnosed Balu's illness as schizophrenia and prescribed medication. Since no one had any information about Balu's family, the local police offered to keep him at the police station. Balu began responding to the medicines he was given as well as to the care he received from the police. His condition stabilised and he began talking coherently. The police gave him small jobs to do and compensated him for the work he completed. Soon the field staff of ADD India learned from him that his family lived in Tirupur. They travelled for ten hours to Tirupur to meet his mother and sister. Today Balu is back with his family. The field staff ensure that the medicines are regularly sent to him and monitor his progress. Even the police constables stay in touch with him!

Soon after the birth of her first child, Rajeshwari underwent a behaviour change. She did not take any interest in the baby, ignored her personal hygiene and got into frequent arguments with her husband. She discontinued sexual relations with him; consequently, he married again. Hearing of this situation, her natal family tried various methods such as visiting temples, black magic and ayurveda. When none of this helped, the family gave up. Rajeshwari remained in an unkempt state and was eventually abandoned by her family. The neighbours intervened and took her to a hospital where she was diagnosed with post-natal depression. She started treatment at NIMHANS, Bangalore. Today, Rajeshwari is well. She also earns about Rs.50/- a day by selling bangles and fancy items. Rajeshwari has been helped through staff of GASS, Karnataka.

Hailing from Siddapura village in Karnataka, twenty year old Shivamma suffered from severe depression and symptoms of psychosis. This is the village visited by staff of Narendra Foundation. Soon after the first symptoms of physical violence manifested themselves, Shivamma's family took her to different religious places, with no results. It was at the mental health camp at Madhugere in Tumkur district that Shivamma first had access to psychiatric treatment. Recovery was almost immediate. However, she stopped medication against the advice of her doctor, and had a relapse. She was then prescribed a maintenance dose of drugs. Again, she discontinued her medicines, a decision she took on her own. The process of medication and recovery brought out her latent qualities, her flair for leadership, clear thinking and a desire to work. She earns Rs. 50/- a day as a casual labourer. In addition, her father and she run a joint business of vegetable vending. Shivamma is stable, looks after herself and supports her family.

These are not isolated cases, but a representative sample of a huge process of change that is taking place in four states of South India – Karnataka, Andhra Pradesh, Tamil Nadu and Kerala. Leading the way for this remarkable transformation is BasicNeeds India, an organization that works in conjunction with partner NGOs towards addressing mental health needs in poor rural and urban communities in Bangalore city. The rural programme in South India is supported by Big Lottery Fund.

Reports indicate that there are approximately 58 million people with some form of mental illness in India. Approximately 3.5 psychiatrists are available for every 1 million of the population, a majority of whom are based in cities[1]. With inadequate support and health infrastructure, human rights violations are common. A case that is often quoted in this context is the fire that broke out in a "dargah" in Eravadi in Ramanathapuram district in Tamil Nadu in February 2001. As many as 27 people were charred to death - they could not be moved out in time since they had been chained to trees. This instance is a vivid testimony of inhuman treatment meted out to people with mental illness. The huge public outcry it raised led to a High Court ruling against such brutal treatment and living conditions.

Data published by the National Human Rights Commission states that 'There are more than 200 psychiatry units of varying sizes with a bed strength of 2 to 200, with an average of 20 beds per unit. The total admission across the centres each year between 1992 and 1996 has been about 9300 admissions each year.' Given the estimated prevalence of mental illness this is grossly inadequate. The National Mental Health Programme (NMHP) is seen as the main conduit for addressing India's mental health needs, but effective implementation is yet to take off. Given this background, it is not surprising that mental illness is a problem that is often neglected. With inadequate mental health care and support, poor persons with mental illness have little hope of recovery or of living life with dignity and independence. The vital need for services for people with mental illness, especially in poor rural communities, therefore became the main focus of BasicNeeds' programme in India.

Registered as a Trust in 2001, BasicNeeds India has developed a unique and powerful approach to deal with the issue of mental health in the context of development. Implementing the model for Mental Health and Development, which BasicNeeds now uses in seven countries, BasicNeeds India works 'with' persons with mental illness, rather than 'for' them. By approaching mental illness within the larger framework of the Disability Act 1995 and adopting a development approach where the voices of affected people are heard, BasicNeeds India works on a larger canvas - much beyond treatment and cure.

[1] Janardhan and Bitopi, Introduction to India and Mental Health in India, 5th edition of E-Journal, Mental Health and Development, 2006.

Organisations	Districts covered	No. of Districts
Grameena Abyudaya Seva Samsthe (GASS)	Doddaballapura, Bangalore Rural District	1
SACRED	Ananthpur Rural Mandal, Ananthpur District Peapully, Kurnool District	2
Narendra Foundation	Pavagada, Tumkur District	1
Samuha	Raichur, Koppal and Uttara Kannada (Karwar)	3
ADD India (Tamil Nadu)	SCORD - Thiruvallur and Tanjore WORD - Podukotai ADD- DIP - Podukotai Federation - Podukotai Voice Trust - Trichy SJDT - Theni and Dindigul Resource Centre - Kanyakumari Esai Trust - Nilgiris	8
ADD India (Kerala)	Vosard-Kumuly, Idukki District TSSS- Kannur	2
Vidya Sagar (Tamil) Nadu	TCT - Vellore IRCDS- Tiravurur TRED - Erode Amara Seva Sangam – Thirunelveli	4

The Primary Partners

Established in 1994, **SACRED** has been working with persons with disability in 40 villages of Ananthpur district and 56 villages in Kurnool district of Andhra Pradesh with the objective of empowering them and bringing them into the mainstream of development.

Set up in 1997, **Narendra Foundation** (NF) has been working in Pavagada taluk in Tumkur district through a community-based approach to ensure dignity of life for persons with disability and their empowerment. NF also works to set up women's self-help groups and networks with organisations for community development activities.

Established in 1996, **GASS** has been working for the empowerment of persons with disability and other underprivileged persons in the community in 150 villages of Doddaballapura taluk. The activities include medical intervention for people with disability through general health camps,

integrated education, self-employment programmes and community development programmes.

The above three primary partners have been working with BasicNeeds since 2000-01.

The Secondary Partners

Action for Disability and Development India (ADD India) works with persons with disability through advocacy, using a rights-based approach. While ADD India works directly in three districts in Tamil Nadu, Andhra Pradesh and Karnataka, they also network with other disability organizations working in rural areas and provide training on the rights-based approach. ADD India has 32 such partners in South India of which 10 partners have been associated with BasicNeeds India since 2003.

The focus of **Vidya Sagar's** work is on persons with cerebral palsy and other disabilities through a Community Based Rehabilitation (CBR) approach. Vidya Sagar coordinates the activities of NGOs involved in CBR work and facilitates the identification of persons with disability, including children. It runs institutional programmes through a school for children with disability, vocational training, human resource development, a PG course in special education for children with cerebral palsy, training of parents, staff and volunteers. BasicNeeds India has been working with four partners of Vidya Sagar since 2002.

Based in Northern Karnataka, **Samuha** has undertaken community development programmes with a special focus on vulnerable people, including people with HIV/AIDS and disability. 'Samarthya,' the disability unit of Samuha, has been working through self-help groups and community-based organisations of people with disabilities at the taluk, district and state levels. Samarthya also acts as a resource group for other programmes on disability issues through training, exposure visits and guidance. BasicNeeds India has been working with Samuha since 2002.

Starting in 2000-01 with three partner NGOs, by 2007 BasicNeeds India had expanded its work to six states covering 38 districts across the country. The programme works in the field of mental health through 13 implementing partners, 40 voluntary organizations and 10 resource partners. At the close of 2007, BasicNeeds India was working with 12,370 persons with mental illness across the country.

Partner staff with BasicNeeds India - A sharing session

However, to really understand BasicNeeds India's work, it is essential to first outline its main tenets and operational approach.

The Starting Years

BasicNeeds works on a simple premise - mental health is a right, not a privilege. Yet for people with mental illness, this principle is not so simple. The reality is that people with mental illness live in a world of stigma, isolation and discrimination. It is also a cause and consequence of poverty.

Set up in 1999 by Chris Underhill, Founder Director, BasicNeeds was registered in the UK as a Trust with the aim of bringing change to the lives of persons with mental illness - from that of neglect to one of rights and dignity. Less than a decade since its inception, the organisation has spread to Ghana, Kenya, Uganda and Tanzania in Africa. BasicNeeds also has ongoing operations in India (South and North), Sri Lanka and Laos PDR in Asia and Colombia in Latin America.

Vision

The basic needs of persons with mental illness, throughout the world, are satisfied and their basic rights are respected.

Mission

Our mission is to initiate programmes in developing countries which actively involve persons with mental illness and their carers and enable them to satisfy their basic needs and exercise their basic rights. In doing so, we hope to stimulate supporting activities by other organisations and influence public opinion.

By the end of December 2007, 54,076 persons with mental illness worldwide had received assistance through various BasicNeeds' programmes that have improved not only their lives but also the lives of their families and care-givers. The Mental Health and Development Model developed by BasicNeeds in 2000 forms the basis of all their programmes.

BasicNeeds believes in the right of persons with mental illness to be consulted, and weaves together concepts of inclusion, treatment, human rights and development. Voices, opinions and perspectives of persons with mental illness and their care-givers form the core of the planning and design of all BasicNeeds' programmes.

BasicNeeds India

Starting operations in 2000, BasicNeeds India Trust was supported initially by BasicNeeds UK. It has been supported by the Big Lottery Fund (UK) since 2004. Since its inception BasicNeeds India has initiated a process where people with mental illness are encouraged to be a part of the decision-making process. BasicNeeds India implements three separate programmes – North India, South India and Urban (Bangalore) programmes.

BasicNeeds India's intervention was designed at two levels - supporting field projects for direct intervention and influencing change in society. The objectives of the South India Programme aim to:

1. Restore mental health and human dignity.
2. Support people with mental health problems to exercise their rights.
3. Alleviate poverty through economically viable income generating activities.
4. Carry out action research and disseminate the information and the results obtained, thereby contributing to the overall body of knowledge.
5. Work with government organisations and NGOs .
6. Focus on advocacy and proper legislation and gender and equality issues.

"Our starting premise was that persons with mental illness, their care-givers and families know what is best for them. Engaging them in a dialogue leads to greater understanding of the issues faced by them which will help in putting together practical approaches to address their issues."

"This was the basic approach underlying all programme design and implementation," explains D.M. Naidu, Secretary, BasicNeeds India.

"Our understanding of the existing situation showed that extreme poverty is a major factor that reduces access to care for people with mental illness. Very often this also makes it much harder for individuals to manage their own recovery," explains Naidu. *"BasicNeeds India adopted an integrated development approach, which also includes sustainable livelihood programmes. This, we felt, could go a long way to reduce the financial difficulties faced by people with mental illness."*

"As we explored further, the scale of the programme became larger. We also realised that separate programmes were required for both rural and urban communities. However, we were aware that it was not possible to do this directly or all by ourselves," continues Naidu. *"Therefore we adopted the partnership approach."*

Partnership implied developing working relationships with groups that could implement the programme at different levels such as community based organizations, village associations, regional and national voluntary organizations and government bodies. *"In this, we were very careful to select partner organisations which shared the same approach and common set of values as BasicNeeds,"* says Naidu.

Values

The programme ensures inclusion of people with mental illness and care-givers equally without any discrimination of caste, tribe, gender, or age.

- Top priority is given to the most disadvantaged groups and to very poor people.
- Respect for people with mental illness and their potential.
- People with mental illness should have equal opportunities for full participation and to exercise their rights.
- Sensitivity to the needs of people with mental illness and responding in a realistic manner.
- Open discussions about the issues and problems of people, whilst maintaining confidentiality. The voices of people with mental illness matter.
- Involvement of the larger community and local resources in taking the issue further.
- Maintaining transparency, accountability, and mutual trust.

The process of getting started was not easy. *"The first step was to gather the first-hand experiences of people with mental illness. We found that, along with them, care-givers also had unique contributions to make, which added to our understanding of the issue. Grassroots organizations working on related issues were also important partners in this process of building an understanding,"* says Naidu.

BasicNeeds India started its first steps through field visits, direct interaction and consultations. This was supported by discussions with experts, researchers and organizations. Information was collated from research reports, policy documents and media reports, which was used to build a better understanding of mental health issues. Says Naidu, *"This knowledge base was used to develop a conceptual approach that was the basis for constructing the guiding principles of BasicNeeds India. These principles were used to direct all BasicNeeds India's future programmes."*

Our belief

Every person, poor and/or ill, has the capacity to manage her/his own life. Therefore persons with mental illness must be included in the development process.

Getting started

The process of getting started required conducting a baseline study, holding field consultations, collecting data of first-hand experiences, sharing experiences, and agenda setting. The first workshop was organized and hosted in Bangalore by The Association of People with Disability (APD) in January 1999. All through early 2000, the core team of BasicNeeds (Chris and Naidu) undertook visits to organisations involved in mental health work in the North and South of India. These included hospitals, care centres run by charities, asylums, day-care centres, private nursing homes and doctors.

"This period was used to assess the status of care available to persons with mental illness in rural areas. Many cases of harmful treatment, faith healing and human rights violations surfaced in these discussions," explains Naidu.

"This laid the basis for intensive field consultations in rural areas to assess their needs."

A unique process begins.....

In mid-2000 NGOs from the three southern states of Karnataka, Tamil Nadu and Andhra Pradesh were invited by Chris and Naidu to begin work on the ground. This process was initiated with the first field consultations with people with mental illness and their care-givers.....

".....A group of women and men gather in a village agricultural co-operative store, which has been lent for the purpose of the gathering. People wait for the bus to bring some participants to the meeting. Staff from SACRED, a small community based organization (CBO), hurry to fetch others on their motorbikes. Shivanna, an elderly man, is invited to sing a song at the beginning of the workshop. His quavering voice rises up like tendrils of sound into the rafters. As he gives new meaning to a well-known mythological tale, the group discerns beauty held in the air like grain dust caught in the morning sunlight.

"The facilitator starts to work with the group and they agree to the ground rules for the morning. All agree that the process writer may record the events of the day. A man unobtrusively pulls out his pad. Like the start of hundreds of such meetings of people that occur all over the South Asian region, an animation session is starting in a small village outside Ananthpur, Andhra Pradesh, India. After some time when the group is feeling more at ease and after sorting out the translation needs common to any mixed language meeting, some realities begin to emerge," writes Chris Underhill, describing one of BasicNeeds' first field consultations held in Ananthpur in Andhra Pradesh.

The participants were invited to articulate their needs and their own responses to the needs stated by them. They were used to form the basis upon which the programme's pillars were erected. Members of community based organizations and staff of other grassroots organizations were also invited to these consultations. A paper titled 'BasicNeeds – A Development Agency Supporting Persons with Mental illness' highlighted the need for inclusion of persons with mental illness in the development process.

A basic premise for the consultations was that the process should be based on the active participation and involvement of people with mental illness themselves and their families in their own development.

A participatory process was adopted using a set of Topic Guides, which could be applied, as required, at any meet. The structure was designed in such a way that Topic Guides were used as 'prompts' with enough room and flexibility to assess specific field situations. The Topic Guides were broadly sequenced in the following order:

- Introduction (Brief about the programme)
- Ice-breaker' game to get the participants to know each other; different

formats were used, depending on the group, its size etc.

- Permission from the group to photograph and process document the meeting
- Setting of Ground Rules (developed together with the participants at each consultation) to be followed at subsequent consultations
- Constituency mapping[2] to identify the people, organisations, or any other constituent(s) who are relevant in 'making up the world' of the group members. It is conducted in small groups, making it possible for every participant to take active part in the exercise.
- Explore the mapping exercise conducted through group discussions 'Needs Listing' exercise. Done in small groups to list the needs/issues that are of concern to the group members i.e. persons with mental illness, their families, CBO staff (and other individuals/groups from the village or community who may participate)
- Exploring listed needs through discussions
- 'What Next?' The last activity (either in full or small group discussions) to initiate commitment from the group as to what they could take on by themselves and to establish in which areas they would need external help to address the issues/needs identified.

The exercise had two major components - 'Needs Listing' and 'What Next?' The former was classified broadly under two heads: appropriate treatment at local level, and follow-up, economic independence and social integration.

Later that year, BasicNeeds India initiated a process of informal but intensive discussions with two of the field-based organisations which had joined them for

A field consultation

[2] This exercise has subsequently been renamed 'My World'.

field consultations - Narendra Foundation in Karnataka and SACRED in Andhra Pradesh. Both organisations made a tentative commitment to work with persons with mental illness and their families in the geographical area where they already had a presence and where they implemented their disability programmes.

This was followed by a two-day consultation with Narendra Foundation - one at Y.N. Hoskote (located five kilometres from the Narendra Foundation office) in September 2000, and the second at Siddapura, where the Narendra Foundation office is located. A two-day consultation was also held with SACRED in Ananthpur around the same time. The process of consultations was used to:

a. Understand the various dimensions of mental health issues in rural areas
b. Assess the ground realities for people with mental illness and their families.
c. Find ways to take mental health interventions forward within the communities.
d. Design interventions linked to the overall development of the individuals, their families and their communities.

People with mental illness - generating collective energy at a field consultation

"Training and skills development almost always emerged as a requirement from field-staff," recalls Naidu. Among the other issues that came up was the need for interventions to facilitate treatment. Some of the participants who were persons with mental illness articulated the need for financial stability, while others stated the need for support in daily care and personal activities.

"This process gave a clear indication of the programmes required. The spot 'needs assessment' was a poignant and clear sign that their requirements were basic, immediate, urgent and, from an intervention point of view, completely unattended to. This manifested itself in their exclusion from all systems/programmes such as health, development etc.," says Naidu. *"This consultative process, by the very act of involving them and getting them to think, speak and express their needs, was a unique one and had never been undertaken before. It also raised their expectations and hope".*

The consultations were also the beginning of creating partnerships with other organizations. To prepare and strengthen them in specific areas of mental health issues a series of discussions, workshops, and training was organized. The assumption was that capacity building of partner organizations was the key to inclusion of people with mental illness in their existing work. This, in turn, would strengthen the direct impact of programme activities. Emphasis was laid on the use of animation techniques and facilitation methods in all the training that was held for demonstration and learning.

Clearly, as stated, 'needs' had to be addressed. Putting together the inputs of the discussions, a model for Mental Health and Development emerged which was regarded as the basic building block on which the programmes were designed on the ground. The components included community mental health, livelihoods, capacity building, research, administration & management. These formed the basis of the model. Later they became modules within the model for implementation.

The Mental Health and Development Model

BasicNeeds' work encapsulates five key components, known collectively as the model for Community Mental Health and Development. These are:

- **Capacity Building** – develops the ability of health systems, communities and persons with mental illness to deliver mental health care.

- **Community Mental Health** – brings easy-to-access and cost-effective treatment to people's communities, often for the first time.

- **Sustainable Livelihoods** – enables people with mental illness and/or their families to get involved in economically viable activities.

- **Research and Policy** – involves generating evidence using the voices of people with mental illness and using these findings to form the basis of BasicNeeds' policy and advocacy work.

- **Management and Administration** – developing systems for partner organizations to ensure the quality of field programmes and optimum utilization of resources.

Over the next year, field consultations were organized around themes such as family visits, workshops for staff and for care-givers, monthly meetings, self-help group meetings and community meetings. All this formed the basis of planning and improving the foundations of the programme. This process led to four main areas of action:

1. Empowering persons with mental illness and building their capacity to become involved in development activities
2. Improving access to mental health services through community based programmes
3. Ensuring the right to work
4. Addressing stigma, discrimination and exclusion from communities and from mainstream development.

Putting Partnerships in Place

Chris Underhill writes, *"Naidu started testing the model for Mental Health and Development in September 2000 with BasicNeeds India's partner organisations, including SACRED, Narendra Foundation and GASS. The basics of how persons with mental illness are genuinely consulted were forged in these important early days. Many of the other ideas incorporated in our model also first took root with these early trials."*

In order to get started, these three organizations, that already had some experience in the issue of disability, were invited as Primary Partners in a spirit and atmosphere of mutual learning. Three larger organizations were subsequently invited as Secondary Partners in order to upscale the programme and expand to larger network groups and spread to a wider geographical area. The core team further felt that advocacy efforts such as lobbying, influencing

public opinion and working with government departments could be more effective in larger groups and would, in turn, benefit the mental health agenda.

BasicNeeds India started the implementation of its South India programme through six partners in three states, Karnataka, Tamil Nadu and Andhra Pradesh. Detailed process documentation was carried out and life stories were collected to collate information as well as to identify the gradual progress of change that could be quantified and indeed qualified by the community and the field staff. The records began to show instances of people getting stabilized, going back to their previous work and joining self-help groups.

Once these foundations were laid in the first three years, a more focused programme was initiated in 2004 with support from the Big Lottery Fund, UK. The proposed outcomes of the programme were:

- The voices of persons with mental illness in the programme are heard, leading to a reduction in stigma and helping to address their rights through supportive policies and programmes
- The development of a South India Alliance of persons with mental illness and community-based organisations who support them
- Strengthening of partner organisations to implement the Mental Health and Development Model
- Understanding and addressing the gender-specific issues in mental health and development through the programme.

The underlying concepts of the Mental Health and Development Model:

The model for Mental Heath and Development used by BasicNeeds India is based on a set of key concepts that underlie the approach adopted by BasicNeeds worldwide. Each of the concepts has been generated through a process of consultation and reflection between various stakeholders and, indeed, people with mental illness. The emerging model is therefore based on an unusual mix of mental health needs and development indicators, placed within a rights perspective.

Holistic approach

The BasicNeeds India model is broad-based in its approach and regards people with mental illness, care-givers and field staff of local organizations as equal and primary stakeholders in the programmes. The model expanded both the existing 'medical model' and the 'institutionalisation approach.' While the former was based on a top-down dependence on a doctor-patient relationship the latter adopted the practice of partial hospitalization, half-way homes and such other institutional facilities for those who could afford 3000-6000 rupees a month. The BasicNeeds India model promoted a holistic approach and adopted a developmental paradigm which was based on the inclusion of all stakeholders.

A rights-based approach

BasicNeeds India advocated a rights-based approach where the voices of people with mental illness and their care-givers was central to the programme.

Seen as active participants in the process of their own recovery, BasicNeeds India linked it to a 'development model' which is anchored within a human rights framework.

A group exercise with people with mental illness

A livelihood component

People actively engaging themselves in livelihood generation activities which, besides providing an income also act as therapy, was an important element of the model. BasicNeeds India realized that illness compounded with poverty becomes a severe trap. However, if income generation was enabled, it would go a long way both for the person and for the family in meeting their basic needs. Hence, the concept here went beyond rehabilitation and expanded its reach to include productivity.

A scientific approach

BasicNeeds India realised that the model had to take into account two important aspects: one, that a scientific knowledge base of mental illness does not exist in the minds of rural people. It is difficult for them to understand that just as for physical illness medicines are available to cure mental illness too. Secondly, knowledge regarding mental illness is overwhelmingly dominated by the local knowledge of faith-healing. This needed to be respected while disseminating information about medical support for mental illness. A scientific approach was to be promoted.

Social inclusion

Social inclusion was regarded as the goal in a community-based situation in order to overcome stigma and discrimination. Once people are included in all

activities, be it religious, social or cultural, and if they can participate fully in such occasions, it would indicate an acceptance by the community. Hence this process-oriented approach aimed at enabling stages of progress in the area of wellness within an enabling community.

Building linkages within the disability sector

In order to make the programme operational on the ground, BasicNeeds India linked their work to other organizations in the field, which were already working in the disability sector. Since mental illness was categorised under the broad spectrum of the Disability Act, this would ensure its inclusion in the development process within existing development practices and health programmes. This would also help to track the accessibility of government schemes, entitlements, grants, loans or special benefits that are available and ensure income generating activities under special reservations. Thus BasicNeeds India advocated a partnership approach which was mutually beneficial, instead of carrying out independent work on the issue.

Yet they all knew that the process was going to be slow. A process where the progress made would be used to learn from and encourage the community, field staff and BasicNeeds' members to continue the learning experience, modifying and fine-tuning the methodology as they went along.

Accessing Quality Treatment and Care

Shanthamma was found roaming in the streets of Manvi by Babu Miya, a senior field worker from Samuha. Since there was no information about where she had come from,, she was admitted to the psychiatric hospital at Dharwad. The team completed all formalities for admission and the hospital staff admitted her to the 'closed ward.'

When Samuha members went back to see her, they found her in a terrible condition. She was squatting on the ground wearing only a blouse. The ayahs were using a hose pipe to wash her as she had soiled her clothes and messed up the floor. Seeing the inhuman conditions and treatment, the staff of Samuha and BasicNeeds India decided to shift her to Gurukula Vidyapita, a short-stay home for destitute women.

But problems arose here as well. Around this time Samuha traced her sister in one of their project areas. She agreed to take Shanthamma back. But soon, her sister found it difficult to look after her as Shanthamma needed trained assistance. The Samuha team counselled her and other family members who once again took on the responsibility of ensuring regular follow-up treatment at the District Hospital at Koppal.

However, the situation was still stressful at home. Two sons left home as they did not want Shanthamma to stay with them. As a result her sister decided to send Shanthamma to Sri Seva Neekethan in Bellary.

With regular medication and proper care, Shanthamma's condition has improved and she appears well and tidy, though she continues to live in a

Looking out at the world after recovery

sheltered home. She has been given a medical certificate by the Koppal District Medical Board and a disability identity card by the District Disability Welfare Officer, which helps her to access the services and support available for people with disability.

The World Health Organization defines mental health as "a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community." The emphasis is on the feeling of well-being, when a person is able to cope with stresses and can appreciate his or her abilities to nurture them further.

The BasicNeeds India Intervention

Given the absence of nationwide or regional prevalence studies and no reliable data, BasicNeeds India found it difficult to estimate the scale of the problem in the project areas.

In the absence of a benchmark study to accurately assess the number of people who may be mentally ill, especially in poor communities, the task became even tougher. Estimates given by the government broadly state that about 15% of the population suffer from common mental illness.

"The starting point for BasicNeeds India therefore was immediate intervention, working with partners and their field-staff in each area to identify and locate people needing treatment," explains Dr. Janardhan, Community Mental Health Officer, BasicNeeds India. "Since these organisations were already familiar with the area and the communities and had previous experience in working with disability issues, BasicNeeds India felt that this was the best possible approach to reach out to the target population."

Diagnosis and psychiatric treatment organised by BasicNeeds India

Tracking the number of persons with mental illness in each specified area, who would be identified for treatment and care, was the first step. "Along with their care-givers, this group naturally formed the first constituency for intervention," explains Naidu. The concept of mental health camps was planned, with a view to focussing on this target group first.

Mental health camps formed an important component of the BasicNeeds India programme in the initial stage. They extended specialist treatment in rural areas. The concept was introduced after discussions with doctors and specialists from NIMHANS. Says Dr. Kishore Kumar of NIMHANS, "Several service organisations organised dental camps or eye camps to reach out and treat patients in rural areas. Yet no group has ever attempted to reach out to people with mental illness."

Partners organised mental health camps in project areas in partnership with specialised doctors. Mental health camps are held on a specific day, when the field-staff accompany people with mental illness and their care-givers to the camp. For instance, GASS holds its programme on the last Sunday of every month, when around 400 people can be attended to . "This day is fixed in consultation with doctors and with staff at the district hospital. Our target community is also aware of this and can plan ahead so that they can attend this camp," says Ravi, Project Coordinator, Mental Health, GASS.

Camps are organised in a central place in the project area where persons with mental illness can be brought for treatment. Two or more doctors are available at each camp along with local volunteers and field-staff of the partner organization. Trained psychiatrists and doctors diagnose and address the needs of local people with mental illness at the camps. This makes it easier for people with mental illness to avail of specialised services closer to their homes. Necessary medicines are also given at the camps.

"Travelling long distances is a huge problem in rural areas. Added to this is the expense involved for travel, as well as the loss of the care-giver's daily wage," explains Ms. Amili, Director, GASS. "As a result, people with mental illness were seldom brought to the Block Level hospitals or to NIMHANS to avail of treatment."

At the camp....

The first step is organising the camp. After the partner NGO makes necessary arrangements at a convenient place, specialists are invited to the camps. The field staff of the local organisation contact individual families and local community-based organisations and encourage and motivate them to come to the camps.

"This process is quite challenging and we have to work hard to get them to believe in the value of this opportunity. The response initially was quite

shocking," recalls Thippanna of SACRED. *"Our field staff sometimes faced situations of violence and we had to provide additional support."*

But once word spreads, the second step is easier. Once they arrive at the camp, a registration form is filled. After registration, the case history is drawn up based on a prescribed format. This is then used for an initial assessment, and medication is prescribed accordingly. People with mental illness are diagnosed and given appropriate medicines. Care-givers are also counselled on taking care of them.

"Most people are administered medication locally. Only more complex cases and those that need further assistance are sent to hospitals for further treatment and care," explains Dr. Janardhan. *"Their requirements for medication are coordinated by the field staff organising the camps."*

"The rationale behind holding mental health camps in rural areas is to be able to ensure that every person with a mental illness receives treatment," says Dr. Janardhan. *"Trained psychiatrists are present for diagnosis, and medicines are provided for treatment. This is a very important step, since most district hospitals are located quite far away and hence inaccessible for most, both in terms of distance and affordability."*

A day at a camp

The time is 10.30 am. It is a bright Sunday morning. The Taluk Hospital at Doddaballapura, near the main bus station in Bangalore rural district is closed for a weekly holiday, yet there are crowds all around.

A psychiatric professional listens to a person with a mental illness

At least 200 people with mental illness have already gathered to attend the monthly mental health camp organised by GASS. Held on the last Sunday of the month, people from the area arrive here to meet a qualified doctor, who listens to their condition, assesses their history and gives medicines as well as advice. They also look forward to meeting the counsellors.

People coming for the first time, or "new cases," (in medical parlance) form a haphazard queue outside the main entrance doorway of the hospital to get their names registered. Those coming for follow-up visits, or "old cases," patiently wait inside the hospital with their case papers to meet the doctor. Along with the people who need treatment are their care-givers.

About 25 field staff of GASS and local volunteers move about briskly, talking, organising and reaching out to answer queries. They organise the queues and send people one by one into the doctor's chambers. Quietly and efficiently they ensure that each person gets a chance to meet the doctor and then help them to collect their required medicines.

The numbers grow steadily in the next hour and include people with obvious mental illness, cerebral palsy and also children with mental retardation. There are several other people who do not seem to be ill in any way, but Ravi explains that they have epilepsy. Murthy is busy checking the files, while Ms Amali reviews the register. Helping them is Shantha, who has been under treatment for the last 15 years for schizophrenia and is now a volunteer.

A number of other professionals such as physiotherapists, counsellors and speech therapists from GASS along with medical professionals from government hospitals are present at the camp. Each specialist meets the person with mental illness and the care-giver. They are given clear instructions on how their wards need to be cared for, the importance of regular intake of medicines, the common side-effects that they will experience and ways of handling them. "This awareness goes a long way in quick recovery and in integrating them back with the community," says Dr Praveen who has come on duty from the Taluk Hospital.

After the camp is over, the staff settle down to make detailed notes for continued follow-up on the old cases and to record the new ones. This includes information not only regarding their medical progress but also about related components - their daily routine, cleanliness and livelihood activities.

All this, till the next month, when the next camp is held.....

"Organising a camp is only the first step for the partner," explains Dr. Janardhan. *"The real work is in the follow-up process."* Reviewing and monitoring of regular attendance, follow-up of drop-outs, side-effects of medication, relapse, and dispensing of medicines are carried out by the local organisation.

"We make regular home visits, meet the family and follow-up on treatment," explains Ravi. As a part of their regular activities, field staff are also trained to follow up on people who have dropped out from treatment, those who have side-effects to medication or those who display reluctance to continue with their medicines, and others who may have had a relapse due to discontinuation of medication. All this helps in tracking people needing access to treatment.

In some cases, camps are organised at Primary Health Centres where District Mental Health Officers attend to people with mental illness who come for treatment and counselling. Resources are also accessed from district hospitals or from the District Mental Health programme, wherever possible. Sometimes private doctors are also invited to participate.

Accessing quality treatment and the care of people with mental illness vary from place to place, depending on the availability of facilities. BasicNeeds India worked on several different strategies to be able to meet the requirements of all people. This includes camps organized by NIMHANS and by partners and accessing treatment from district hospitals, mental health institutions and private psychiatrists.

Diagnosis and treatment are of two kinds. The first case is where people with mental illness are taken by field staff to camps held by NIMHANS in various places. The second instance is where people are taken to a camp organized by a partner organisation for diagnosis and treatment, or to district hospitals.

A person with a mental illnes with her husband - seeking family support

Monitoring the individual progress of affected individuals is an important activity of the field staff. Like many others, Venkatesh of GASS reviews the regular intake of medicines by people with mental illness, the completion of daily chores, their hygiene and food intake. "The more difficult indicators such as motivation to work, awareness, insight into their situation and willingness to comply with societal norms also need to be recorded. This is not always possible as these are somewhat intangible."

The progress made through treatment helped to create awareness and demystify the myths about mental illness. Initially home visit reports by staff revealed human rights violations, harmful treatment, environmental barriers as well as ways and means to deal with such situations. Over time, stabilization, a return to previous work, involvement in some gainful occupation, joining self-help groups and other activities demonstrated to the community that people with mental illness can be treated, that mental illness is treatable like any other illness.

"We track the progress of women very closely," says Gowramma, Women's Coordinator, GASS. *"This requires close scrutiny, as women tend to ignore their medication and other needs easily."*

BasicNeeds India designed an Individual Rehabilitation Plan (IRP) to systematically monitor each individual's progress, to track the growth and recovery of each person under treatment over an extended period of time. The IRP is the most important source of the organized database. Records of every individual identified during the course of this programme are maintained by BasicNeeds India.

Taking a break after a focus group discussion

The treatment given at mental health camps leads to visible signs of recovery in people with mental illness. Changes in behaviour and improvements are noticed. They involve themselves in work and participate in social and cultural activities. Consequently the attitude of their care-givers also becomes positive.

The field-staff are also trained in the responsibilities care-givers have to take on. This forms a part of the monitoring process. Care-givers, in turn, form an association where each person can share their difficulties and look for support. This provides relief to them and becomes a platform for cross-learning.

Says Ramachandran of ADD India, "The Care-givers' Association plays an important role in building a sense of solidarity among care-givers. This support plays a very important role in the lives of care-givers who often need sustenance for their never-ending and thankless jobs."

Care-givers' Association

People with mental illness and their care-givers are encouraged to form an association of their own. This provides a platform for them to discuss various problems. They share them with other members and find solutions.

For example, Basvaraj's family experienced unwelcome reactions from the community when he was found wandering in the streets. The Care-givers' Association in the village took on the responsibility of explaining the illness to others and asked them to be considerate to him. Basvaraj was able to return to work as a labourer.

In another case, the Care-givers' Association took the decision to advocate for the right to treatment. The association members met the district authorities and explained the need for treatment to be made available at the block level. People with mental illness and their families decided to voice their needs rather than depend on local organizations. A psychiatrist was deputed to conduct mental health camps at the local health care centres on a monthly basis. Medicines were also distributed at these camps.

Impact

Besides individual data records, the cumulative impact of the intervention is evident in many of the reports and documents. It is clearly evident that better medical support and treatment have been made available to people with mental illness and that care-givers have an improved understanding of the condition of the wards they are in charge of. The interventions made people with mental illness recognise their own capacities and responsibilities in terms of personal care and hygiene, the absolute need for regular and timely intake of medicines, a changed attitude towards care-givers and other family members - all of which have a positive impact on the entire family.

"Rani, my daughter, had been mentally ill for many years. We used to chain her and lock her up in the house. When the field workers came, we used to

hide her. Then we saw the changes in other people who took medicines. We asked the field workers for assistance in accessing treatment. Rani has now stabilized and this has changed our lives completely." Rani's mother.

There is, besides, evidence of change in people's attitudes to mental illness. If dommunity members identify mental illness early enough, they realise that timely treatment is critical to avoid chronicity. There are instances when field staff have brought down their interaction with people with mental illness and their families from weekly to monthly meets. All this is testimony to the change BasicNeeds India's programme has wrought.

Closed Ward, Dharwad

In 2001, the community based programme of Mental Health and Development was started in a small community in Raichur district of Karnataka, where Samuha was leading the process. This led to an increased awareness and understanding of mental health in the community. Issues such as the causes of mental illness, the types, the treatment process and the roles of the care-giver, family and community were discussed. The programme focussed on the larger participation of the community, while reducing the emphasis on institutionalization.

This exposure created change. Earlier people with mental illness went to the psychiatric hospital in Dharwad, commonly called the Closed Ward. The Ward was over 100 years old and could not provide adequate treatment or support to the people who came there. Unaware of the consequences, people either reduced their dosage or discontinued their medication completely. This led to a relapse and the whole cycle of illness and treatment and visits to doctors for medication had to be started all over again. Shanthamma's case mentioned earlier is an illustration of this.

Samuha worked to form small groups of people with mental illness and took them in batches for treatment to the psychiatric hospital. However, Samuha encouraged them to continue living at home and not get admitted to hospital, thereby encouraging a community approach to institutional care. The community was promised support from the programme staff in case of any problems. This encouraged community members and care-givers to learn to be disciplined, yet sensitive to their needs.

Volunteers from Samuha made sure that people with mental illness continued their treatment and took them to the hospital regularly. They also followed up on them. People began to show improvement and recovered while continuing to live within the community. They were also encouraged to take up small jobs or agricultural activities for livelihood purposes.

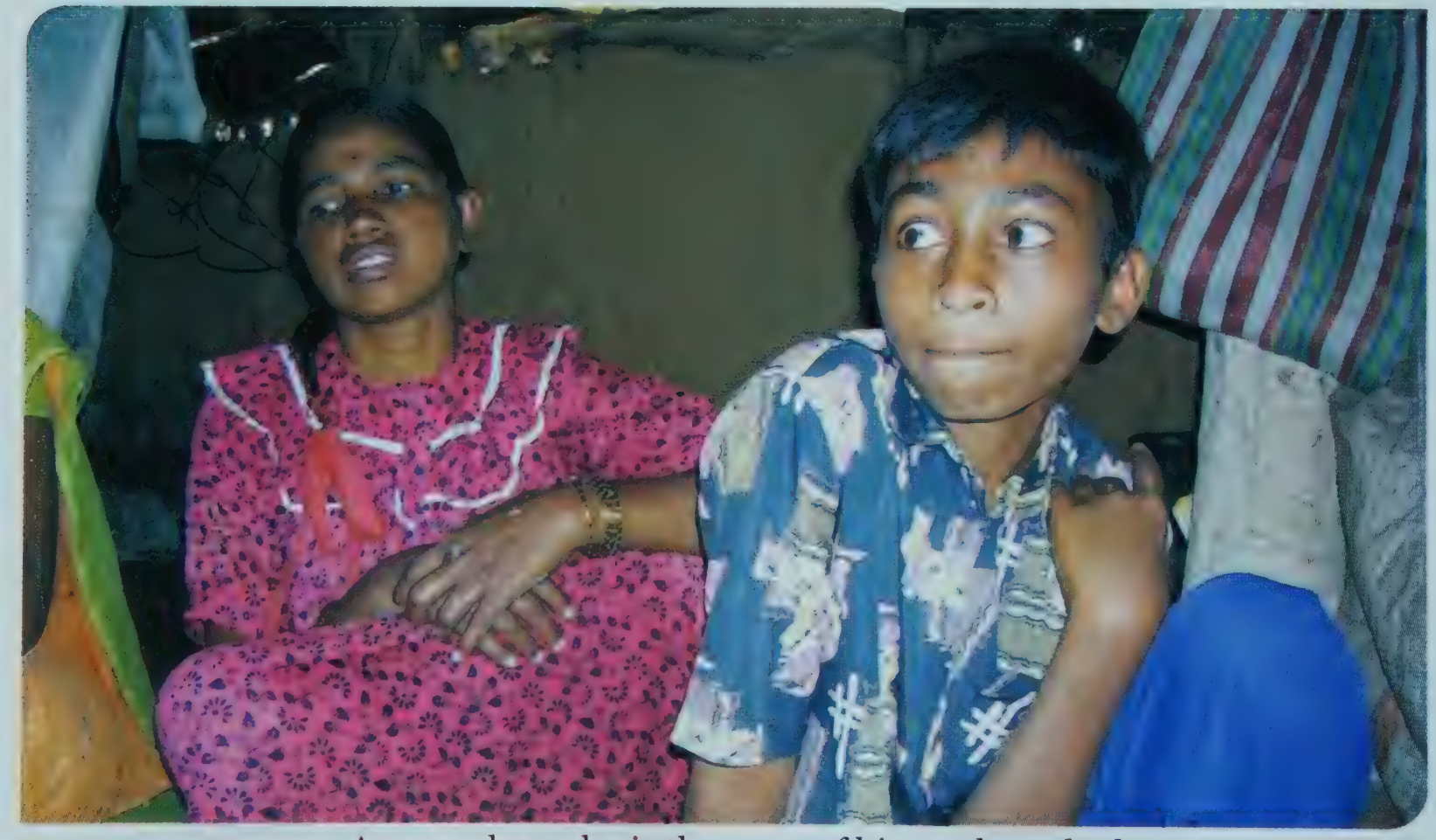
Facilities were made available at both district and block levels. Regular follow-ups and family support led to a dramatic reduction in hospital visits and admissions to the Closed Ward. This experience was an indication to the

government that a community based programme could actually reduce admissions in the hospital. Subsequently, in 2004, the hospital issued orders for the closure of this ward. This was indeed the end of a process of institutionalisation which had been operational for the last 100 plus years.

Challenges

In spite of all the efforts to track the improvement of people with mental illness and making treatment facilities available, many challenges remain that need to be addressed in a more rigorous manner. For instance, the availability of transportation for accessing treatment is a serious problem. The distance involved from the home to the camps acts as a deterrent due to inadequate public transport facilities. Often this was one of the most obstructive factors in providing access to care and treatment.

"The role of the care-giver in this whole process is often under-estimated," says Ramachandran of ADD India. *"This is indeed unfortunate as they have a critical role to play in the process."* Accounting for the care-giver's time and availability is not taken into account in the process of care and treatment. The care-giver has to act as an escort to the person with a mental illness and bring them to the camp at the stipulated time. In addition, the care-giver incurs loss of the day's wages, as most of them are daily wage labourers.



A young boy who is the carer of his mother who has a mental illness

Monitoring and review visits are also not planned for. Regular and timely availability of medicines is another shortcoming which affects the progress of the person with mental illness. This assumes greater importance as regular and timely medication is the key factor in avoiding a relapse.

The partners also find that alternative, traditional, harmless, healing practices continue to prevail. While BasicNeeds India's principle does not contradict this practice, it is aware of the fact that the continuity of harmful practices could have adverse effects all around.

There is no counseling facility for minor problems. The camps mostly review the complex cases and people with severe mental illness. Other complexities such as the presence of physical illnesses or disabilities, symptoms of HIV/AIDS or substance abuse make recovery an extremely difficult task to accomplish. In addition to this is the need to recognise variations between the issues that affect rural and urban societies, which need separate strategies for intervention.

"The special needs of women with mental illness require attention and sensitive handling. This is often overlooked, and women continue to suffer the double burden of mental illnes, gender issues and, of course, poverty," says Ms. Amili. *"We have appointed a full time lady psychiatrist at our centre at Thiruvallur."*

Despite the efforts of field workers, drop-outs are common. "In such cases, field workers tend to see their efforts as a failure. We have to constantly motivate them and reinforce the importance of the work that they are doing," explains Thippanna of SACRED. *"Yet it is a constant challenge for us to train field staff and retain those who are experienced in their work."*

Total number of people receiving treatment (December 2007)

Partner organization	Male	Female	Total
SACRED	170	111	281
Narendra Foundation	139	133	272
GASS	316	448	764
Samuha	712	869	1581
ADD India and Vidyasagar	1057	1114	2171
Total	2394	2675	5069

Padmavathi, Siramalu's wife and care-giver, who lives in Narayanapuram, a village in Ananthpur Rural District in Andhra Pradesh, has an interesting comment on the situation.

Soon after her marriage, Siramalu began to show strange symptoms and odd behaviour. This became frequent and erratic. The family tried to get local treatment, which helped, but he would always relapse. There seemed no future for him or his family.

In one of the self-help group meetings, a member narrated the story of Siramalu to the field staff of SACRED. They took him to the District Hospital where he was diagnosed for bipolar affective illnes and given medication. He started treatment and began to show improvement. Regular visits to the doctor helped to monitor his condition and uninterrupted treatment enabled him to maintain stability and attain significant improvement.

Padmavathi's brother helped to get Siramalu a job in a transport company where he earned Rs.120 daily. His employer finds him very sincere and hardworking and appreciates his work, a commendation he makes to Siramalu's wife when she comes to collect his salary. Padmavathi earns a small income through selling fried snacks. Their joint income has enabled them to educate their two daughters and their son, who have studied up to high school. He then began working at the power looms and contributing to the family income.

Would her children take care of her later? Padmavathi replies, "My husband is healthy; he has the capacity to earn and take care of us. Why should we depend on our children? We can lead a happy life. All my life I have struggled to take care of my husband and my family, and I was able to handle all the problems that came my way."

Regular medication, support from her brothers and the community and her personal will power have helped Siramalu and Padmavathy reach a state of self-sufficiency and well-being.

Ensuring Dignity Through Livelihoods

A minor altercation in Rachanpalli village in Ananthpur district in Andhra Pradesh grew out of control and resulted in some villagers getting seriously injured and hospitalised. Shortly after, Akullappa, a daily wage labourer, went to see his injured relatives in hospital, and underwent a behaviour change. He became scared and insecure, constantly locking doors and forcing his family to hide, fearing an attack.

His wife, Rudramma, also a daily wage worker, took him to a local faith healer at Kondupuram. Though she spent over Rs.1000/- there was no improvement. Akullapa's behaviour became aggressive. Chikka Akullappa, his younger brother, suggested that he be kept tied to a tree outside the house.

But his elder brother, Dodda Akullappa, suggested that Rudramma should take him to NIMHANS in Bangalore for treatment. Akullappa was diagnosed with schizophrenia and put on medication. He recovered completely. However, once home, they lost the prescription and were unable to get the required medicines. Akullappa refused to go back to the hospital, and he relapsed. His erratic and aggressive behaviour pattern surfaced again.

One more visit to the faith healer at Gutti was made. It brought no improvement, and the expenses were heavy. Sujatha, SACRED's field worker, called Rudramma to a self-help group meeting where she met many other women with similar problems. She also came to know of the monthly mental health camps conducted by doctors from NIMHANS at Gowribidanur.

Rudramma took Akullappa to the camp. With regular treatment and follow-up, Akullappa's condition stabilised. He was able to return to work as well as continue with his treatment. His steady income of Rs. 50/- a day helped to put his children back in school. Akullappa is aware of his condition and the need to continue treatment. He never misses his monthly review meeting at Gowribidanur and is regular with his medicines. He also started meeting and encouraging other people with mental illness to go to the camps.

Recognising his efforts, Akullappa was made President of the self-help group for people with disability. Rudramma is also a member of the group and takes part in the savings and thrift scheme. Akullappa has formed a group with three other villagers and they jointly undertake contract work in agriculture, a venture from which he earns about Rs. 2000-2500 a month. The village community admires his recovery and the efforts he makes for the economic development of his family.

Though the term 'livelihood' is interpreted in many different ways, it basically implies the ability to earn an income which sustains or increases the capability to meet the basic needs of life. The importance of this definition has a special significance in the case of mental illness. A sustainable livelihood is an

opportunity for people with mental illness and their family to work their way ou of poverty. This is doubly important since people with mental illness are ofte stigmatised due to their illness and forced out of employment. Lack of income added to the increased cost of medicines and care, forces them into a spiral o poverty.

Engaged in livelihood activity

BasicNeeds India views sustainable livelihoods as an essential component to help persons with mental illness earn a living. Beyond just earning, BasicNeeds India believes that this is vital to their long-term recovery as it secures their treatment and builds a sense of self-esteem and confidence.

In fact, employment is also instrumental in combating stigma, whereby common perceptions that people with mental illness cannot contribute to their family's income are challenged. BasicNeeds India stresses that once persons with mental illness demonstrate that they can be productive and constructive enough to make a worthwhile contribution to their family and their community, the stigma they face will reduce and even disappear.

A close link between livelihood generation and availability of micro-finance was also encouraged by BasicNeeds India through its programmes. Several stabilised people have undertaken new enterprises through the availability of micro-finance. It is an enabling factor for enterprise development. Accessibility to micro-finance has been recognised as a revolutionary process in development.

Horticulture as therapy

Micro-finance increases the options and the self-confidence of people by helping them start an enterprise, expand it and, at times, add other businesses to it. Further benefits include an improved consumption pattern, higher returns on investment, increased productivity and an increase in income. Additionally, income can be saved, which can provide an interest component as well. All this collectively contributes to an improved quality of life.

Livelihood activity as ther..

In the context of persons with mental illness, regular medication bring about a condition of recovery, which enables them to exercise better control i their daily lives and re-enter productive employment. The BasicNeed programme identifies the capabilities of individuals and helps them return t their previous employment or find new work. Often, people learn new skil required to start a micro-enterprise and are supported in their efforts to acces credit. Therefore, meaningful work makes a visible contribution both to th person and to the family's well-being ,promotes recovery, and transforms the wa a person with mental illness is seen, both from within and outside the family Thus, the sustainable livelihoods approach is an effort adopted by BasicNeed India to reduce both exclusion and the economic burden of the family facilitating acceptance and reintegration into family, community and society.

Specifically, the programme outlines the purpose of livelihood generatio activities:

- To enable people with mental illness to participate in sustainable, self-relian income generation programmes, leading them to exert their full potentia within their own communities
- To enable people with mental illness to engage in an activity, which i physically and mentally challenging, yet rewarding, and in turn promote improved physical and mental well-being
- To enable the families of people with chronic mental illness to undertak income generation activities, which will serve to augment the existing famil income, thereby alleviating the financial burden of caring for a person wh needs long- term care.
- To reduce medicine intake over a period of time as people becom successfully rehabilitated within their local community through productiv activity and regain their self-worth.
- To provide an opportunity for families to come out of the debt trap which has in many cases, caused or aggravated the mental illness.

Basically, having a livelihood is often therapeutic. It enhances earnin capacity, reduces dependence on others, and provides some relief to care-givers The programme approach gives stabilised people the option to go back to thei previous work; however, if that is not possible for various reasons, then field staf help in trying to get other alternative jobs that they may be capable o undertaking. For example, Horticulture.

The partner NGO also assists in securing government loans or grant through schemes available for people with disability, which is possible at th panchayat (local government) level itself. Since a 3% reservation fo employment is provided for all persons with disability, the family is treated as unit and, in the case of poverty or chronicity of illness, support can also be give for any other member of the family to access schemes and facilities to start ne livelihoods for income generation.

- The activities performed by the field staff to create livelihoods begin initially through an assessment of the recovery of the person with a mental illness. Only after that can any work schedule be planned. After getting stabilised the person has to learn once again to focus on a specific activity for a longer duration of time. This may be gradually enhanced beginning with shorter spells. The employer is also educated about this aspect so that the steady recovery process continues uninterrupted. Field staff are trained to recognise this pattern in people and begin the next step of engaging them in meaningful work. Other activities of field staff include
- Emphasis on regular intake of medicines
- Ensuring nutritious food for maintaining good health and to be able to work efficiently
- Encouraging people with mental illness to join self-help groups.

Field-staff are also trained to assist in securing loans from various schemes for people with disability, and to help with looking for new avenues or for markets for special products. Another important aspect of their work is an emphasis on the side-effects of psychotropic drugs, made clear to all care-givers.

Thirty year old Krishnappa of Kanakagiri village in Koppal district in Karnataka began showing signs of behaviour change. Says his father, *"One day, I had a minor difference of opinion with my son and he asked me to get out of the house and stay with my daughter. He kept shouting at me and even came to hit me."*

Krishnappa was shackled and taken to KIMH hospital in Dharwad where he was admitted and put on medication. His condition improved and he was discharged. Unfortunately, once home, he stopped his medication and had a relapse. The family took him back to the hospital. This time, the family gave a commitment that they would ensure that he took his medication regularly, despite the cost of the medicines, and that they would travel to Dharwad for it.

It was at this time that Samuha informed them that treatment and medicines were available at the PHC at Kanakagiri. Krishnappa started going by cycle to the Kanakagiri centre to get his medicines himself. This saved a lot of money for the family. Krishnappa also started working in the field and his average earning came to about Rs. 500 per month.

His father says, *"We are grateful to Samuha for having brought treatment so close to us. This has helped us save money and improve our son's health. He brings his medicines on his own."*

Krishnappa says, *"I am feeling better. I am taking my medicines regularly. I keep my medicines in my pocket the previous night itself so that I don't forget when I leave for work in the field. I want to earn more and look after my family. I want to educate my children and take care of my parents in their old age."*

At the monitoring stage, it is essential that field staff recommend work schedules after ascertaining the ability of the individual to focus on specific jobs for a longer period of time. It is important that the person shows interest and motivation to do meaningful work. This ensures quality of output and continuity of work without absenteeism. Noticeable improvements like getting back to a routine and doing daily chores are indicators of recovery and need to be monitored. This is particularly important when the person is involved in decision-making in the family and plans to take up newer types of income generating activities and is able to attend the monthly meetings with field staff.

Rearing goats to sustain self

Self-help Groups

A group of 12 women in Erumalainayakanpatti came together with the help of the St. Joseph Development Trust (SJDT), one of ADD India's partners, to form a self-help group to address the persistent poverty that they faced. They started a savings programme, through which each member saved Rs. 100 per month. The members planned to buy a buffalo once a sufficient amount was collected. This would then be a source of regular income as the milk could be sold at the diary cooperative at a guaranteed rate per litre. However, one of the women lost her husband to a snake bite. The members deferred their plans for the purchase of the buffalo, and rallied round to support her and help her tide over her tragedy.

Ananthaveni, the Treasurer, has schizophrenia. Her condition has stabilised through medication. She derives the same benefit as all the other members of the group. Together, they work towards meeting the needs of the individual, the group and the community.

Impact

The impact and the change in stabilised people demonstrates very positive features. These include resources to meet basic needs, increase in food intake, increase in purchasing power, and even the ability to cope with new demands. The additional income enables them to come out of the debt trap (that most families slip into), actively participate in self-help group meetings, guide others who are ill, disabled or need livelihood options. They are also able to demand and get entitlements available to them from the government and other agencies.

A recovered person with a mental illness, milking his cow

Many prefer to continue with the job they were doing prior to the onset of their illness. In a few cases, people have adopted a new livelihood activity. Many have got their job cards under the National Rural Employment Guarantee Scheme (NREGS) and earn Rs. 80–120 per day for their contribution.

Critical change factors with livelihoods for persons with mental illness after stabilisation:

- Confidence
- Finance
- Training
- Market and trade analysis
- Motivation
- Family support
- Community support (mainly as customers)
- Courage

The income generated through the livelihood is as important as the tremendous increase in confidence and self-esteem that people with mental illness experience. *"Being productive and relieving the care-giver also enables social inclusion, as the community views the person as a productive and contributing member and not just as a liability,"* explains Naidu.

Income generation activities undertaken by different partners include:

- Organizing orientation programmes on animal husbandry as an income generating activity.
- Income generation loans have been given to 1191 people with mental illness. Loans have been availed from their savings, government schemes, banks etc.
- SACRED has been successful in influencing the Society for Eradication of Rural Poverty (SERP), Government of Andhra Pradesh, for getting Rs. 55,000 towards income generation loans for 35 people.
- Housing under Indira Kranthi Pathakam, a state government programme, has been availed of by 22 persons.
- People with mental illness and their families in Kerala have accessed government schemes under local panchayats for livelihood programmes.
- 18 villages were chosen under 'Indiramma Gramams - A Model Village Scheme.' Under this scheme, every person with a disabling condition is eligible to avail a disability allowance, ration cards and housing facilities.

Most people with mental illness, even while on medication, are involved in household activities. Though some of them are not fully stabilized, they do not need constant care and are able to contribute to domestic chores such as washing vessels, cleaning and other household work.

"Also, because they are able to look after their own needs, it is possible for the care-giver to take on some other productive work," explains Thippanna of SACRED. *"This adds to the family's income and takes away from the sense of frustration all around."*

Income generation activities include weaving, goat and sheep rearing, cattle rearing, petty shop trading, vegetable vending, blanket weaving, tailoring, repair and maintenance of electrical and electronic appliances, agriculture and vermi-composting etc. The average income from such activities varies from Rs. 500 to Rs. 3000 a month.

Challenges

Amongst the several challenges faced by the BasicNeeds India programme, creating livelihood options for affected people remains the most crucial challenge. One obvious issue remains - that of continued support from field staff for new avenues of livelihood. This is because field staff encounter continuously voiced demands for increased benefits. The dilemma is to determine the right time to withdraw and make people self-dependent.

Another issue is in the larger context of the community. It is often observed that community members fall behind in their responsibility because of the availability of special schemes that favour people with disability in the area of economic development.

A strange but true situation is encountered by the field staff of SACRED. They confirm that persons with mental illness are unwilling to recover because of the 3% benefits that they receive! This, according to them, is the perfect way to live since they are able to access these special benefits for a longer duration.

These concerns plague programme staff, and answers are difficult to find...

In the case of support to partners too, an important question that remains unanswered is, "What level of support is to be given to field staff in terms of income generating activities and other training?" This also goes beyond the text of the programme and additional resources have to be found if livelihood options are to be explored adequately. These issues will have to be addressed in planning exercises as the programme expands in future.

Amali from GASS states that out of six people identified for loan eligibility in a quarter, only one was actually capable of undertaking income generating work. The other loans were taken by the care-givers who took them in the name of the person with a mental illness and used them to start an income generating programme. "Though not planned, this approach also has dividends. Since the family is able to earn more, they are able to meet the additional costs incurred in taking care of the person with a mental illness," she says.

Narendra Foundation - linkages were made by the community for people with mental illness and the watershed programme initiated in the area through a World Bank project.

- Yarramma, Yashodamma and Chinnamma have been linked to the Jala Samavardhana Yojana Sangha from the Ponnasamudra Nagalabhavikere Tank Management Institutions (TMI). Rs. 2000/- was given through the Disability Sanghas.
- Ramakka from B.K. Halli and Nagalakshmi from Thimmammanahalli villages have been supported for livelihood activity through a Disability Sangha's link with the 3% GP reserve fund. They have taken up goat rearing. Members of the Disability Sanghas have the responsibility of monitoring fund utilization and how they repay the amount to the groups.

Yet it is only when people with mental illness are able to earn their own income and contribute to the family's resources are they regarded as equal players in the community.

Number of people stabilised and now working in different trades, December 2007

Activities	No. of people
Agriculture & agro based coolies	1371
Business	218
Domestic work	1378
Tailoring / Agarbatti making / other IG activities	350
Skilled work	143
Studies	121
Govt/private employee	53
Total	3659[3]

No. of people who have joined self-help groups - 2963
No. of people who have been able to access loans from the government - 478

Sethu: A tale of market and trade analysis

Sethu had a mental illness, but he has stabilised sufficiently to be able to run a small enterprise selling cooking ingredients. Before he started, he spent time assessing the various ingredients in greatest demand, (such as pepper and coriander), and estimated the demand for them.

Sethu moves about on his bicycle selling small packets of condiments tailored to the needs of low-income consumers who purchase their daily requirements from him at competitive prices. He travels around 35 kilometres every day on a pre-set route and has built up a network of established customers.

Though he dreams of buying a motorcycle and covering a larger area, he is also aware that this would push up prices for his customers and could actually damage his business!

[3] Statistics for BasicNeeds South India programme.

Spreading and Scaling up Through Alliance Building

A large hall at Loyola College at Chennai was bustling with over 250 people milling around. They comprised mainly of people with mental illness and their care-givers. After a quick breakfast, everyone was ready for the day. Some of the participants were called to the dais and awaited their turn to speak, while others eagerly waited to hear them.

Suddenly, one of ADD India's field staff noticed that Devappa was missing! He panicked. Then he recalled that Devappa had been fascinated by the trains at the huge railway station when they had arrived in the morning. Perhaps his curiosity had led him back there. Sure enough, Devappa was found at the station, and brought back to the venue.

Presentations and discussions continued through the morning. Small group activities were designed to enable everyone to participate fully. After lunch, games and simple exercises were planned. The evening ended with a popular 'film star' enacting small roles that left the entire hall ecstatic. All the participants felt happy, active, socially included and completely satisfied, though exhausted by the end of the day....

A village community gathers to participate in a BasicNeeds' programme

Increasing the impact of development initiatives to large-scale coverage can be approached in a number of ways. It can be done through direct organizational growth and programme expansion, whereby model replication and adaptation remain the main methodology. It can also be achieved through

demonstration projects in other areas which adopt this methodology. Another kind of scaling-up is of indirect organizational growth which can take place through catalysing and supporting partners or joint venturing and alliance building.

Alliance building is one of the main strategies of the BasicNeeds India programme for scaling up and expanding the spread of the programme. This approach requires the formation of an association with primary partners, secondary partners and resource partners as well as individuals committed to the issue participating as volunteers.

Scaling-up through catalysing and supporting partner organizations, both primary and secondary, has been a key activity of the BasicNeeds India programme since its inception. Though the process of alliance building began simultaneously, along with the development of the programme in the field, it took formal shape only in 2007.

How did it start?

As a part of the planning process, BasicNeeds India looked towards setting up alliances at different levels. The first level consisted of primary partners. Partnerships were formed with SACRED in Ananthpur district of Andhra Pradesh, Narendra Foundation in Tumkur district and GASS in Bangalore district of Karnataka state. These three organizations had previous experience in working with disability issues, and thus enabled a spirit of mutual learning.

This was followed by scaling up to secondary partners for a wider reach. The next step was to identify large, reputed development agencies and involve them in community mental health. The first partnership was made with Samuha. Subsequently, Action on Disability and Development India(ADD India) and Vidya Sagar were invited to promote and work with persons with mental illness in 12 districts of Tamil Nadu. Fourteen development agencies involved in community based rehabilitation came under the aegis of these large organizations.

The secondary partners worked as 'mini BasicNeeds Indias' with numerous groups following the model. Secondary partners directly dealt with resource organizations and planned and implemented the programme in the field. Given the technical nature of the work, another level of alliance building created by BasicNeeds India was of resource partners. They were first identified through an intensive process of selection.

Vision

Set up as an unregistered, informal body, the South India Alliance aims at joint efforts towards creating an environment where people with mental illness lead a life of dignity. Starting in 2007, the alliance, 'Action Oriented Platform of People with Mental Illness, Care-givers and Federation of Disabled' is a new

concept where collective strength can act as a catalyst for building advocacy on issues related to social justice for people with mental illness.

Building membership

The Alliance is open to membership and can include any institution or individual who is supportive of the issue. Individuals who are interested in this issue or are actively involved in the programme are inducted as volunteers. People who have stabilised also frequently volunteer to be a part of the Alliance. Others volunteer when large gatherings are organised and additional manpower and resources are needed. The Alliance is therefore open for support from all.

The South India Alliance is the broad umbrella for all the three states in its initial stages. Each State has its own alliance of care-givers, partners and institutions. Volunteers are welcomed to join and support the issue.

"The process design is such that there is no inbuilt hierarchy or structure," explains Ramachandran. *"Unlike a forum or a network which has office-bearers and assigned roles and responsibilities for members, the Alliance has a flat structure. The effort is to have a level platform for free and fair discussion of issues and identification of alternative solutions."*

Membership of State level Alliance

Andhra Pradesh	211
Kerala	240
Karnataka	770
Tamil Nadu	1210
Total	**2431**

Activities of the Alliance

Various activities are undertaken through the Alliance. At an institutional level, a preliminary introductory meeting was held to outline the nature of the work and assess the ability of the key partners to participate in the activities of the Alliance on a regular basis. These include NIMHANS (National Institute of Mental Health and Neuro Sciences, Bangalore), KIMH (Karnataka Institute of Mental Health, Dharwad) RINPAS (Ranchi Institute of Neuro-Psychiatry and Allied Sciences, Ranchi), The Banyan and SCARF in Chennai, Jayanagar General Hospital, Victoria Hospital in Bangalore, District Hospitals and mental health professionals.

A major activity of the Alliance ever since its formation has been organising Alliance Meets. Lead roles are taken by each partner for various activities, and responsibilities are shared within the Alliance. Partner organisations volunteer to organize the forums at different times of the year and people with mental illness, their care-givers, field-staff and heads of organizations participate. These meets also serve as a platform for formal and

informal discussions where people engage in sharing of problems and looking for solutions. They get updates on the latest news, and relevant information is disseminated. These discussions help to access benefits, plan ways of approaching what is missing on the ground, formulate strategies for working with the government and, more importantly, build evidence and lobby for such requirements. Persons with mental illness along with their supporters (they could include self-help groups to which they belong, marginalized groups and other people with goodwill) lobby with appropriate departments for accessing their entitlements.

The meets also enable a cross-fertilisation of experiences and ideas of partners which enhances the understanding and efficiency of the field staff. It also greatly strengthens commitment to the issue and demonstrates solidarity in terms of the numbers involved.

The Care-givers' Association and self-help groups are an integral part of the alliance of partner groups so that their agenda and activity can be strengthened through collective effort.

At a meeting of the Tamil Nadu alliance in Chennai, about 14 NGOs and their field staff from the state, well known psychiatrists, senior government officials, academicians and well-wishers met along with people with mental illness under the aegis of ADD India and Vidya Sagar, which had organised the Alliance Meet in December 2007.

In January 2008, an Alliance Meet was organized in Thiruvananthapuram, Kerala, with the objective of bringing together the stakeholders of mental health and development from Idukki and Kannur to share their journey, their challenges, and to plan the future. The programme was also used to sensitize the government and the public on mental health. Around 115 people from Idukki and Kannur districts participated in the one-day programme. Other ADD India partner NGOs from Ernakulam, Thiruvananthapuram and Kottayam also participated.

Occasions such as World Mental Health Day on October 10 are marked by a major event involving all Alliance members. Responsibilities related to planning a meet, the logistics and accessibility are worked out and divided amongst all participating organizations. A triangular formation of groups, members of self-help groups, members of the Care-givers' Association and field staff get together to draw attention to the issue and take it forward.

World Mental Health Day, Bangalore

Impact

The concept of alliance building is indeed young, yet its potential is powerful. Started in 2007, the impact that this has had within a year is somewhat hard to quantify. Yet BasicNeeds India is aware that consolidating the processes that have been initiated and, indeed extending the model to other areas, can only be possible through building alliances. The number of members has grown steadily. At the end of 2007 there were 2431 members already enrolled in the South India Alliance.

The Alliance Meets showcase the model of Mental Health and Development in a manner that well-wishers interested in getting directly involved, supporting, volunteering or informally participating in the effort, are able to view its processes clearly. The presence of core staff members of the organizations at the Meets is in itself a show of solidarity and strength.

Having a stabilised person chair a meeting or a group activity is clearly a positive sign of the impact of this intervention. This demonstrates the leadership qualities that people have within them. It demonstrates that despite the mental illness they once had, they are able to take on responsible positions and undertake activities in a dependable manner.

"The Alliance has also greatly strengthened the relationship between organisations. We use these forums not just for cross-learning, but for appreciating each other's work as well. It also helps in disseminating best practices," says Ramachandran. *"However, more importantly, the issue of mental health is a complex one. It is an empowering experience for our field staff to see the commitment of so many others and the work they carry out."*

In order to strengthen experience-sharing, each of the secondary partners publishes a newsletter in the local language for wider dissemination of information. This effort enables access to information on relevant topics and encourages suitable action. The contents outline topical concerns and relevant issues while informing partners about planned activities.

Manasu – Association for persons with mental illness and care-givers
This four-page six-monthly newsletter brought out by ADD India in Tamil called Manasu is circulated to all 14 organizations in the State. The slim publication carries information on relevant issues and has directives that are relevant for people with mental illness in the state of Tamil Nadu. Updates on events, services offered and questions and answers on mental Illness are some of the highlights of this publication.

Vikasinchina–Manasulu is a newsletter in Telugu published by SACRED. This four-page publication states the vision and mission of the organisation and the objectives of the mental health programme. News is included of local events such as Mental Health Week celebration, training programmes, services available for people with mental illness, along with true stories of recovery.

Samuha Samarthya is a twenty four-page monthly news magazine published by Samuha in Kannada. While the contents include information on the issue of disability, there is a strong focus on mental illness. The contents include guidelines and a checklist on the care and support of people with mental illness, for eg. how to prevent suicides and injuries. Simple guidelines for ensuring mental health, such as the importance of sharing thoughts and feelings with people close to us, are also included in the publication. A regular column by Dr. C.R Chandrashekhar of NIMHANS is the highlight of the newsletter along with case studies and life stories. The newsletter also contains updates of news, events, and a doctor's advice on mental health.

Challenges

The challenges to this process are indeed many. Chief amongst them is the problem of language in the development of a South Indian Alliance at the regional level. Experience shows that when the meets are state-specific, a healthy interaction follows; however, when it involves other states, several difficulties are encountered. Each of the presentations, discussions, games, songs, needs to be translated into each of the other languages. Not only is this tedious and time-consuming, it also limits direct interaction among the participants.

Furthermore, since the practice of alliance building is not a formal one, sourcing continuous support is a challenge. Groups with limited finances find it difficult to organize such Meets and meet all the logistical costs.

In spite of all these challenges, alliance building has had significant impact on the ground. For instance, the essence of Alliance can be noted from the following statement from BasicNeeds' records, 'On completion of the first year, BasicNeeds India invited all the people involved in the programme directly as well as indirectly, and who have contributed towards the development of people with mental illness to share their experience and provide suggestions for further progress. Hence, a two-day get-together was organized in May 2005. This was a gathering called to reflect, review and understand the status of the programme. The reviewers, partners and friends of BasicNeeds were present at the programme. 'Partnership,' based on which the whole programme works, is a significant achievement of the programme. This was quite evident from the many people who had come together to reflect and learn from each other.'

Or as Regina, a mental health worker, puts it simply, "The experience of working with people with mental illness gives me a sense of peace in life....."

The BasicNeeds South India family

States	:	Four (Andhra Pradesh, Karnataka, Kerala, Tamil Nadu)
Districts	:	21 districts in South India

Partners

Primary	:	SACRED, GASS, Narendra Foundation
Secondary	:	ADD India, Vidya Sagar, Samuha
Resource	:	National Institute of Mental Health and Neuro Sciences (NIMHANS) Bangalore Karnataka Institute of Mental Health (KIMH)–Dharwad The Banyan and SCARF – Chennai M.S.Chellamuthu Trust – Madurai

Resource Persons

Private Psychiatrists	Advisors
Dr. Ajay Kumar	Dr. L.S. Saraswathi
Dr. Anbudurai	Mrs. Valli Seshan
Dr. Ayappan	
Dr. Radha Shankar	

Network Partners	Well-Wishers	
Jana Swasthya Abhyan	Dr. Elangovan	Dr. Prabhakar
CEHAT, Mumbai	Dr. Vijay Kumar	Dr. Geetha
BAPU Trust, Pune	Dr. Kishore	Dr. Nambi
Anjali, Kolkata	Dr. Kalyani	Dr. Chandrashekar
Snehi, Delhi	Dr. Shekar	Dr. Karur
	Dr. Bijole	Dr. Mali Patil
		Dr. Nagesh

Creating Change
Influencing Policy and Public Opinion

In Kannada, 'huchha' is a derogatory word that is commonly used for a man who has a mental illness, while 'huchhi' is implied for a woman. These are age-old terms that over time have come to humiliate and embarrass the person concerned. Indeed, the baggage of stigma is inbuilt in the word "mad" itself.

Being sensitive to the choice of words used by all its staff members, BasicNeeds India explained the importance of changing the terminology to the community. The stigma and misconception associated with terminology were highlighted. It is to their credit that they have been successful in doing so. Now persons with mental illness are referred to as 'manasika aswasthe', which means 'mentally unwell.'

This small but significant change indicates a deep change in public opinion, which in turn can go a long way in reducing stigma and discrimination in the communities.

The stigma attached to mental illness has had a very deep impact on people with mental illness and their families. People with mental illness have become the victims of discrimination and human rights abuse. In some cases, discrimination starts within the family, perpetuated by relatives, and goes right up to policy makers and state authorities. As a result, they face chronic ill health and are treated as an economic and social burden, leading to destitution. Marginalisation in the form of being chained, locked up in rooms, forced to stay in the closed wards of asylums and hospitals are other manifestations of the stigma associated with mental illness.

"BasicNeeds believes that mental health is a development issue. We believe that people with mental illness should be included in every development process. It is their entitlement," says Shoba Raja, Director, BasicNeeds. The slogan adopted by BasicNeeds India is, 'Right to be treated, To be treated right.' "To enable this, all BasicNeeds' activities work for change in and around the person's location. This is followed in our South India programme as well."

At another level, joining forces with other groups and organizations is a key strategy in building a critical mass that can impact major national and global initiatives for influencing policy and public opinion. BasicNeeds seeks to do this by working at different levels – from the grassroots to the international level. "While information technology has facilitated information sharing and assisted in joint campaigning, we have also observed that some of the most effective advocacy campaigns and lobbying efforts have taken place through local networks of organizations, groups and individuals - each with similar and partially shared objectives," explains Shoba Raja. "And these have been able to influence policy decisions." Advocacy and policy work have thus become significant.

An important aspect of BasicNeeds' advocacy work is enabling the poorest people to speak for themselves in the design of the intervention process and articulating the same in international and national decisions which affect their welfare. "Our partners also believe in this approach and are building mechanisms for the 'voices' of people with mental illness to feed into policy processes," says Shoba Raja.

Making linkages

Adopting a rights-based approach, BasicNeeds India believes that everyone, including people with mental illness, has the right and ability to live with dignity. This has been one of the major non-negotiable principles propagated by BasicNeeds India which reiterates that every person has a right to health needs, to human rights, and also to economic, political and civil rights.

In the context of people with mental illness, an important setback is the exclusion the person faces from the family, the community and society. It is therefore important to explain and emphasise the need for and the goal of social inclusion in every public forum.

Says R.K. Doss, Secretary, Women's Organization and Rural Development (WORD), Podukotai, Tamil Nadu, *"We were unaware of the needs of people with mental illness; we work with people with physical disability. Now we have incorporated them in our agenda and attempt to integrate them with society."*

"Initially this was hard, and required a change in our own perspective. The changes that have taken place in the lives of people with mental illness due to the attitude and behaviour change towards them is extraordinary. We also have several volunteers who work with us and support our programmes," he continues.

Training and building capacity

Several capacity building exercises have been designed to help field staff, care-givers, family members and self-help group members understand the concept of rights, giving them instances of human rights violations in treatment and related issues. The emphasis of these training programmes is to build a positive attitude that does not give prominence to personal tragedy, but builds on entitlements that they can avail of. This also includes an understanding of why mental health is a development issue.[4]

'We need to understand that mental illness is like physical illness and can be treated. In India, 1% of the population suffers from severe mental illness, 15% suffer from common mental illness and 5% from substance abuse. We need to eradicate this just as we have eradicated major diseases like malaria. But due to

[4] Many of these processes are documented extensively and continuously updated within the organization to develop further need-based training programmes.

ignorance of the problem, mental illness still remains a major issue. Many beliefs are deep rooted and changes need to take place at the community level. The foundation for change is participation. Policies or acts cannot be effective unless we all work together and share our responsibilities.' - Dr S. Nambi, Secretary, State Mental Health Authority – Chief Nodal Officer, DMHP, Government of Tamil Nadu.

A training programme

The training modules are designed to foster skills development and alter dominant thinking. The programme is fundamentally designed for the people themselves and their care-givers and families. Training for field staff includes the understanding of different types of mental illness, mainly the common and the severe kind. It also includes a component on basic counselling skills, basic medication, issues related to side-effects and relapse, and emergency measures.

Similarly, training for general practitioners includes information by experts on psychosomatic illness, details of medicines available for different types of illnesses, early identification and referrals to psychiatrists.

Another component of the Mental Health and Development model, termed Capacity Building Exercises, addresses several complex issues that question deeply entrenched attitudes such as stigma and discrimination. A novel approach adopted is the Animation Technique that involves the group in a selected issue. Other interaction methods involve regular discussions at meetings, consultations and workshops where doubts and apprehensions are cleared.

Field staff at a meeting

These learning-teaching formats have been carried out by BasicNeeds India through a process of dialogue that develops around words and themes. The discussions generated give space to the participants in the training programmes to analyse and question the realities behind terminology, accept the harm that they may have caused, construct alternative visions, and reflect on the strategies by which these visions could be brought closer.

Listening to documented life story

Research

As a core activity outlined in the Mental Health and Development model, research, especially theme-based research, has gained importance. Two central issues, namely, field perceptions of the Mental Health and Development Model and a care-givers' study have been initiated within the BasicNeeds India project :

1. The aim of the first study is to understand the perceptions of the Mental Health and Development Model by people in the field. The primary objective of the study is to understand the experiences of the various players involved in supporting and implementing the model. This uses a descriptive research design for collecting information carried out on a) field-staff of all partners directly involved in its implementation, b) people with mental illness and their carers (especially those who are stabilized and show some progress), c) other service personnel especially in the areas of education, social welfare, health in general and mental health, d) community leaders and e) general public (men and women of different caste groups). On completion, this study will provide insights into the model that will enable its further modification and strengthening.

2. In taking care of people with mental illness, their care-givers play an important and difficult role, especially when their wards have severe mental illness. Their role is as much recognized as the need for medicines and doctors. Care-givers have a responsibility which can weigh against their own health and their mental health as well. Hence it was considered important to examine the role played by care-givers in helping people with mental illness make progress and get stabilized. On completion, this study will help in supporting care-givers to keep up their own health and spirits to continue with their responsibility of caring for their wards. It will also serve as a resource to the Mental Health and Development programme's training component and guide those who are being introduced into the programme.

In addition to this are Life Stories which are narrations by people affected by mental illness – narrations of their experiences of having mental illness and also of their progress towards recovery. Narrating their story enables them to speak about themselves and have what they say, listened to. This is therapeutic and provides rich insights, sharply bringing into focus the viewpoints of persons with mental illness.

An important aspect of the documentation process is collecting every significant detail in the life of the person with a mental illness. This is explained to all field staff, so that nothing is missed out. This is especially necessary in the case of people with mental illness whose lives need to be recorded in a narrative fashion. Life Stories become important pointers for further analysis. Specially formulated guidelines have been developed to list the details that are required for constructing a good life story.

Making an impact

The efforts to influence policy and public opinion were directed at different levels. They included using people to influence policy as seen with regard to activities in the project areas. Two instances demonstrate this at the district level:

- The community mental health service in Koppal district is a successful enterprise of public-private partnership in the health sector. Under this framework, government and non-governmental agencies have been successful in providing mental health services to the community for the past three to four years. As many as 2000 people with mental illness have been registered under these services. Outreach psychiatric clinics in four taluks provide services. However, the clinics have been burdened with an ever-increasing number of patients. This has necessitated the need to know the magnitude of the problem in the community and at the primary health care level, as this would help in planning and implementing the mental health programme in a much better way.

- Accessing livelihood options at the panchayat level available in the form of government schemes/grants/job cards has been positive, availing entitlements for people and demonstrating changes in public opinion. These benefits were made available after field staff procured the documents and made this information known at the local level to enable them to access these benefits. This enabled greater and more appropriate utilisation of government schemes for people with disabilities.

State-level

Similarly, implementing the District Mental Health Programme at the Public Health Centre level, access to other health needs, educating the employer about sensitivity towards an employee with a mental illness, educating other community members such as anganwadi workers, self-help group members, were all part of the strategic efforts towards changing policy and public opinion.

Change in public opinion has also been facilitated through street theatre. People with mental illness often act in these performances, share their experiences at public gatherings and motivate others to take treatment for their illness. Often in a question-and-answer session deep-rooted beliefs and myths are addressed that help people reflect, discuss and realise the harm that this can cause to the suffering person.

Partner organizations have also come up with unique approaches to address the doubts and reservations that people may have. Instances of such activities are phone-in programmes broadcast over the radio every week, the use of video films and mass media for depicting commonly known problems such as depression or epilepsy. All of this helps in spreading awareness that in turn helps in changing perspectives.

BasicNeeds India commissioned a film on the life of a person with a mental illness. This film showcases the journey of Lallapa, his illness, his

recovery, his support systems - his wife and the organization. It also highlights his improved condition, focussing on how he is able to earn a living and take on the responsibility of his family.

This film will be used in raising the general awareness of different audience groups, in training programmes and in influencing donor agencies.

A major initiative in this effort was to introduce the concept of rights and work towards preparing a draft on the Bill of Rights, which was based on the awareness that people with mental illness are not enjoying their rights. A workshop was held in Bangalore in 2006, in collaboration with Bapu & Anjali, where care-givers and the legal fraternity made a commitment to evolve a Charter of Rights. The meeting was an opportunity to learn from initiatives people used to address problems when faced with dilemmas. The workshop was also used to identify the rights that needed to be included in the proposed Charter.

D.M. Naidu, Programme Manager, BasicNeeds India, at a discussion on the Bill of Rights

At another level, formal structures like the police and the judiciary have started to take note of these changes in the community and have learnt to differentiate between criminals and people suffering from mental illness.

However, the most important changes have been within the Health Department where a significant improvement is noticed. The collaborations and networks formed with several leading mental health institutes, private doctors, research organizations and other development experts have had a cumulative impact. Cross-learning has taken place to every person's advantage. For instance,

- General practitioners were given training in psychosomatic ailments and they learnt to treat people accurately

- In several rural areas, the District Commissioner took an active interest to see that proper services were made available. This has brought about a significant transformation in the attitude of concerned officials, which has been noticed by the people with mental illness who approach them.

Another component is related to women. Conventionally, women are sidelined where treatment is concerned. Men get preferential treatment. Women with mental illness are the worst hit, especially in rural areas. In informal discussions and other debates, partners have expressed that they focus on women and that women with mental illness have been included in mainstream women's activities. In many cases, the majority of care-givers are women, and in some cases, young girls.

People's Health Movement

All these efforts converged in March 2007, when hundreds of health activists, health workers, health care professionals, public health experts and concerned citizens gathered in Bhopal, Madhya Pradesh, for the 2nd National Health Assembly organised by the Jana Swasthya Abhyan (JSA).[5]

BasicNeeds India took the initiative to participate in the Assembly and requested the organizers to provide a platform to present mental health issues in India. Along with other participating organisations, BasicNeeds India facilitated the two-hour parallel session and made use of the opportunity to spread interest in mental health issues among the 2000 odd health activists and organisations participating from all over the country. A detailed critique and feedback from the mental health perspective to refine the position paper 'Towards a People's Alternative Health Plan' is underway. It will be sent to the JSA National Executive.

Challenges

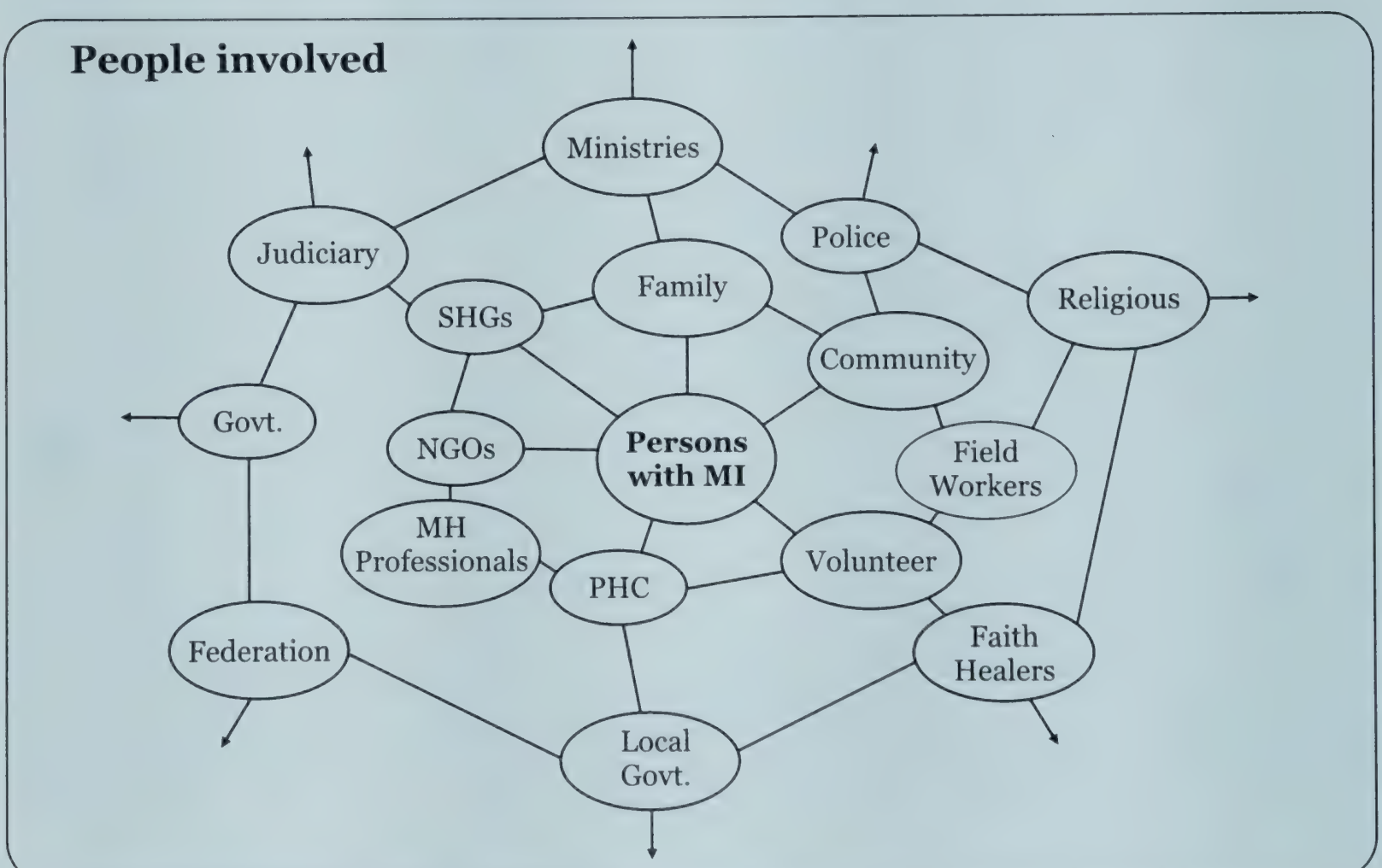
Yet, the situation continues to be that mental health is a low priority area not only with government public health systems, but also with civil society forums such as JSA. Though this national forum offers opportunities for various issue-based groups to draw support for each other's concerns, a greater emphasis is needed on the disability and mental health sectors.

Experience has shown that human rights violations against people with mental illness are a common practice. Given the indifference and neglect, BasicNeeds India's approach of promoting a rights-based cause such as Right to Care, Right to Well-being or Right to Wellness was a challenge. The broader context of mental health and well-being needs to be strengthened.

[5] The Jana Swasthya Abhyan is the Indian circle of the People's Health Movement, a worldwide network of individuals and organisations united in their understanding that health is a social and political issue and above all a fundamental human right. The JSA is based on the belief that ensuring that every citizen enjoys a basic Right to Health requires the involvement of not only the medical fraternity but of people from a large number of disciplines such as law, economics, social sciences, media and communication.

In order to be effective, BasicNeeds India believes that it is essential that the association between human rights and development is recognised as vital in the case of people with mental illness. Since the emphasis in the Indian Mental Health Act is limited to custodial care, BasicNeeds India along with other national organisations has started work towards building a comprehensive Mental Health Policy.

An area being explored by organizations such as BasicNeeds India in their advocacy work is the link between human rights and development, or the 'Rights-way' to development. This is a fundamental challenge to the view that prevailed since the 80s. This emphasis by human rights groups indicates a major shift from a needs-based approach to development, to one based on internationally-agreed rights, entitlements and obligations. The rights-based approach may well be a new development strategy – which has great significance in the sector of people with mental illness.



Holding the Model in Place
Management and Administration

Given the scale of the Mental Health and Development Programme and the various dimensions to it, the importance of an efficient system of management and administration was quite apparent, from the very beginning. This is why Management and Administration is built in as one of the five modules of the model. Strong emphasis is given to this, right from the start of all BasicNeeds' programmes worldwide.

The backbone of the BasicNeeds India programme, and indeed its strength, lies in the efficient management of its project. Defining a 'project,' as understood in the development context, the need for multi-level project management, setting up of management information systems, are all essential ingredients that BasicNeeds India set in place to manage the South India programme efficiently.

BasicNeeds India recognised that the advantage of a good project plan lay in providing a conceptual framework, within which detailed information on specific issues could be collected and analysed. The BasicNeeds India team worked towards designing concepts which included specification of objectives, design, inputs, activities and projected outputs. Accordingly, they were also used to clearly define the need for specific expertise and manpower and the roles and responsibilities delegated to them. In the context of its projects, management information systems at BasicNeeds India are designed for optimization. This is a set of organised procedures which specify norms or criteria for information required, the process, appropriate methods of data collection, analysis and reporting formats that capture all the relevant information, and for a mechanism by which information can be used as a feedback to influence the activities of the organization.

Naidu explains, *"The team believed that a good project plan would encourage a conscious and systematic examination of alternatives and facilitate control and proper accounting of funds, both by implementers and fund providers."*

The Big Lottery Fund, which supported the project since inception also maintained that the need for accountability and efficiency had to be built into th system itself.

Within BasicNeeds India itself....

Much of this is laid down in the MOU which is drawn up by the project partners. Each partner agency enters into a detailed contractual obligation with BasicNeeds India which clearly lays down the spirit of the partnership as in *'to share the belief that people with mental illness have the right to self-determination in all areas of human development, and hence have joined*

together to support them in their effort for justice and equality.' This is followed by a statement of values and relationship, in addition to the plan of action, organisational roles, budgets and mandatory components such as resolution of disputes etc.

See Annexure for MOU

Implementation

Partners begin their activities once the MOU is signed. The agreements are renewed every year with each of the partners and new activity schedules and budgets are drawn up through mutual consultation.

Quarterly reports are submitted by each partner, which are based on the five change criteria[6], information on CMH, existing cases, new data, livelihoods, training etc. They also include a financial report.

The reporting system follows a process that begins at the field level and moves upwards and gets consolidated by the primary or secondary partner, as the case may be. The programme reports of the partners are consolidated by BasicNeeds India and sent to BasicNeeds-UK. The financial reports of each partner are sent individually to BasicNeeds-UK. To ensure regular monitoring of activities, quarterly reviews are carried out with the partners by project managers who review the programme and finances and offer any other support that is required at the field level.

A review meet with partners

[6] BasicNeeds uses the following five change criteria: 1. Impact on the lives of poor women and men with mental illness and their families 2. Change in policies, practices, ideas and beliefs 3. Change in gender balance/equity 4. Stakeholder involvement in the change process 5. Sustainability of change.

Grants are released to the partners on a quarterly basis, on receipt of the previous quarter's reports. Research, reviews and evaluations are carried out annually at the close of the year by external agencies. Partners are trained, based on their expressed needs.

In terms of operational management and partnership administration with community organisations and alliance partners, the Individual Rehabilitation Plan created for every person with a mental illness is an important tool. Other reporting formats are process documents, monthly meeting reports, quarterly reports and annual reports by each of the partners. They are collated in the main office for the preparation of a cumulative report for the global office and for use on the website.

Other global systems to which BasicNeeds India contributes is 'VOICES,' an intranet, where a monthly internal newsletter features key events and developments from each programme. "VOICES" is a forum for recording and circulating activities, life stories. It also lists the actions to be carried out by the programme teams.

Alongside this is the E-Journal, 'Mental Health and Development,' which features relevant issues pertaining to global mental health. One particular country is highlighted in each of the editions and several papers are hosted relating to the work carried out in the country. The journal consists of different sections called 'Focus', 'Beyond Boundaries' and 'World Watch.' Altogether they cover diverse issues related to the main theme. Edition No. 5 covered BasicNeeds India and its programmes.

E-Journal: www.mentalhealthanddevelopment.org

In its efforts to advocate mental health issues, especially in the context of rural communities, BasicNeeds started an E-Journal called Mental Health and Development on its website.

'As BasicNeeds expanded more and more globally, we realized that our experiences with mental health and development had much to contribute to academic research and we would also benefit from their research and ideas. This dialogue can go a long way in promoting mental health as a development issue.' - Director's Message – Sixth edition, 2007.

The journal synthesizes information about the situation of persons with mental illness the world over and serves as a forum for discussion and exchange of ideas in mental health and development. It chronicles new developments and analyses emerging trends in the field.

The E-Journal presents the knowledge gained and achievements and challenges experienced by all BasicNeeds' partner organizations from all country programmes. The aim therefore is to make this informative, interesting and stimulating to all - medical professionals, academics, development experts,

students, organizations, indeed, to all those who are committed to and interested in mental health aspects.

Support has been growing and new networking alliances are building up in Australia, South America and more countries in Africa and Asia.

In addition to management practices, financial accounting has also been given attention, to ensure systematic and transparent systems.

BasicNeeds India's activities are led by the Programme Manager, D.M. Naidu. Supported by an experienced Board of Trustees that works in a spirit of 'Hands on, eyes on', the slim organisation has a flat and flexible structure.

Looking Back, Moving Forward
Impact, Challenges and Future Direction

"The most impressive aspect of the project is its success in mainstreaming the issue of mental illness into existing development organisations. This has enabled mental illness to be dealt with holistically, addressing the three areas of concern identified by people with mental illness – treatment and stabilization of their condition, income generation and social integration." Joanna Monaghan, Grants Officer, Big Lottery Fund, after a visit to the programme in 2005.

While it is premature and perhaps difficult to assess how the initiatives will be sustained once the partners withdraw and leave communities to manage the process that has begun, what is evident is the willingness among the people to continue the activities and processes started. In fact this is true not only of care-givers, but of partners too.

While this is a hugely pertinent indication of the impact that BasicNeeds India has had and the strength of the processes that it has stimulated on the ground, the impact of its project is evident at two levels – the tangible and the intangible. In tangible terms, available data indicates the number of people who have benefitted from this programme and the increase in their number over the past five years. However, more important is the change that cannot be quantified by data, and yet is truly at the core of what the project sets out to achieve.

To enumerate them:

Impact on the lives of poor women and men with mental illness and their families: Undoubtedly the most important element of assessing change is the direct impact that the intervention has had on the lives of people with mental illness. This is evident in terms of change - in access to treatment through camps, district hospitals, DMHP, private practitioners, and NGOs. The economic burden of personally procuring medicines is considerably reduced. This is significant as the programme is advocating for the availability of medicines from the government and people becoming free from symptoms.

Further change is evident in the economic situation through vocational training such as skills training in tailoring, incense stick manufacturing and other small enterprises that have increased family income. Treatment made locally available has diminished the financial burden of spending money on travel.

The Mental Health Coordinator of Narendra Foundation says, "We are now saving time and money because doctors have come forward to conduct camps at the Pavagada Health Centre. Before, we had to travel three hours to reach Madhugiri camp, and then back another three hours after it finished."

Changes in Policy, Practice, Ideas and Beliefs: Change in the larger context both at the policy level and in attitudes is by far the most difficult to bring about in a social environment. BasicNeeds India has had significant impact in influencing policies for change, lobbying with the government, both at the national and local level, with academic institutions and other bodies associated with this issue[7]. Stigma, for instance, has been addressed, signalling changes in attitudes and behaviour. Other activities aimed at mass awareness such as street theatre and group training for the community have also been instrumental in this transformation. Changes in people's ideas and beliefs have also been observed. BasicNeeds India notices from the way the community reacts that they now believe that mental illness is treatable.

Changes in Gender Balance/Equity: Gender-disaggregated data on participation and the changed roles of men and women have indicated that the number of women who have access to treatment is equal. This is significant, as in previous situations women with mental illness were doubly marginalized.

Several reports show that 'nearly equal numbers of men and women have been treated in South India.' Data indicates that more women than men have accessed treatment. A gender sensitization workshop was carried out in the early stages of the programme for all partners to be able to have conceptual clarity on this issue, and for recording the unique elements of this process of change.

Stakeholders' Involvement in the Change Process: People's participation in the programme for people with mental illness is one of the most critical aspects of the BasicNeeds India approach. Significant change is evident in the participation of persons with mental illness in the social life of the community. This is visible where people with mental illness are able to participate in community life and in the decision-making process. Many people with mental illness have become volunteers and help field staff by providing follow-up services and by taking on other responsibilities. Many community groups have also begun to assist the field staff in their activities. Participation is evident at all levels, across a spectrum of activity.

Sustainability of Change: The emergence of strong self-help groups which include people with mental illness, networking with partners and field staff and collaboration with them indicate the scope of the alliance being built. These alliances help in sustaining change within the project areas, and also in influencing change in nearby areas. There are many supporters from government agencies like the Department of Health and Family Welfare, the police, judiciary, NGOs, federations and child development programmes who form a part of this alliance. Schools have also joined in to discuss the problems of people with mental illness in their districts. These are indications of the sustainability of change.

[7] For instance, associating with the Tata Institute of Social Sciences, (deemed university), which invited BasicNeeds India for the National Consultation Workshop for developing a course on mental health and development.

At a different level, field staff have become more sensitive towards the effects of common mental illness on daily productivity. This constitutes the staff of 20 organizations under the aegis of 6 larger organizations spread across 21 districts in the 4 states of South India. This includes a total number of 100 field staff who have directly learned from the inputs of this programme. Not only have they learnt about issues related to people with mental illness, but they have also been exposed to the pattern of working within the development context, which is the essence of the Mental Health and Development model.

BasicNeeds India also uses the voices of persons with mental illness as the most effective tool to campaign for issues related to human rights violations and social exclusion. Some partners have been innovative in addressing these issues and in networking with the local government and NGOs to influence public opinion. At Samuha, the staff and local bodies are influencing district authorities, advocating for the right to treatment and the availability of medicines at local Primary Health Centres.

The biggest change is evident in the case of people in the community who have come to regard mental illnesses as treatable. Volunteers help in identifying people with mental illness and encourage them to seek treatment. These initiatives indicate a dramatic shift in attitudes towards people with mental illness.

Mass awareness programmes have also played an important role in creating a positive impact, especially with reference to reducing stigma towards mental illness. Street theatre, radio programmes and interactive programmes with the community have helped to create a positive environment for people with mental illness. Partners have been able to secure funds from donor agencies to continue the programme.

In terms of pure numbers...

In an effort to locate as many people with mental illness as possible in their specific project areas, and understand the direct impact of the project in the last four years, the South India programme's internal review carried out in May 2006 states that, 'All 6448 women and men with mental illness from the blocks of 21 Districts in Southern India have been benefiting from the community Mental Health and Development programme initiated by BasicNeeds India through partnership with 6 organizations. 77.16% of the people who have been identified have been assessed, diagnosed and treated directly, contributing to the main outcome of the project. People with common mental illness constitute 2975; whereas people with severe mental illness constitute 3364. These numbers are significant, as the main outcome of the project is to work with 4500 people with mental illness by the end of four years, and to make 70 % of the people identified have access to treatment.'

The total figure also includes 155 people who have died since the project began due to physical ailments and geriatric problems. Out of 4891 people with

mental illness, 1234 have stopped treatment as they have reached the pre-morbi level of functioning. This constitutes 77.16% of the specific population. Also, 348 people with mental illness have stabilised and are involved in productiv activities[8].

A significant number of people with mental illness have accesse treatment facilities through psychiatric camps, NIMHANS's neuropsychiatr extension camps, district hospitals, private psychiatrists and district menta health programmes. A total figure of 4578, to be exact. Resource partners suppo the activities of partner organizations in their operational areas, and camps hav been regularly held. Furthermore, psychiatric medicines have been mad available at the block hospitals of 15 districts, namely, Raichur, Koppal, Karwar Pavagada, Doddaballapura, Ananthpur, Podukotai, Thanjavur, Tiruvaru Trichy, Erode, Tirunelveli, Theni, Kanyakumari and Dindigul.

People Identified with mental illness in the South India Programme (31st December, 2007)

	Male	Female	Total
No. of People reached	**3244**	**3204**	**6448**
People with severe mental illness	1828	1588	3416
People with common mental illness	1416	1616	3032
Number of people under treatment	2125	2262	4999
Number of people stabilized	1675	1845	3521
Number of people earning doing productive work			**3069**

At an indirect level

While direct impact is perhaps easy to identify, the indirect impact of th programme is sometimes as much, if not more, important. A look at a cross section of the more indirect or intangible impact, and related issues:

Care and support

The impact of the programme can be understood in its entirety when th influences different stages of the programme. This includes the changes observe in the families and communities in whose midst the programme happens. Sever indicators show people's changes in behaviour, attitudes and beliefs when peop with mental illness participate in all activities, like the rest of the community. Th community is able to identify people with common mental illness, who can acce

[8] BasicNeeds India's 14th Quarterly Narrative Report, 2007

early treatment facilities. Often field staff are sensitive and able to recognize the onset of mental illness among care-givers too. There is improved understanding and people with mental illness and their care-givers give attention to personal hygiene and matters of physical health. Families also understand the impact of abuse and refrain from using shackles or any other form of restraint to keep their wards under control. BasicNeeds India believes there is now a reduction in admission to mental hospitals and that along with the supervision of treatment, families take the responsibility of caring within their homes and communities.

Inclusion and economic development

With the recognition that mental illness is treatable, families realise the capabilities of a stabilised person and provide support and persuade him or her to accept new opportunities that are available for learning skills, starting enterprises or jobs. Other people in the communities come forward to offer jobs and respect the newly acquired skills. People co-operate and are now visible at cultural and family functions. Stabilised people with mental illness are now able to volunteer during camps by doing work like registering the patients who come, sharing their experiences and distributing medicines along with the field staff of the organizations. Existing self-help groups also show interest in addressing the problems of people with mental illness and their care-givers and offer solutions, in terms of opportunities that may be created through reservations or special schemes. They continue to act as pressure groups and encourage their members to go in for regular treatment and are a source of support to the families. These small but diverse efforts work towards a better quality of life for all members of the community.

Commitment and Capability

Partner organizations have continuously been exposed to diverse issues. They get strengthened in their resolve and commitment to work for this cause. They accept their work and understand the seriousness of mental illness. They continue to create awareness and facilitate the inclusion of people with mental illness in the community. These groups not only identify people with mental illness in their villages, but also provide follow-up services. Field staff are trained to identify people with common mental illness, and receive skills training so that they can provide counselling to people with common mental illness. They have learnt to use the disability clause to access schemes, grants and loans the government has made available for people with mental illness. Cross-learning between partners in problem solving, accessing information about allocations and other aspects has also taken place.

Mandate

Many of these organizations have been able to convince donors and they have now obtained independent funding. This implies that the teams are now capable of handling such programmes by themselves. It also indicates that donors are recognizing the need for separate funding for issues related to mental health, which is distinct from disability or community based rehabilitation

programmes. In fact, in one instance, the issue of mental health has become suc
a part of their mandate that all their programmes must now necessarily have
mental health component built into them. This change in perspective on the pa
of donors is a welcome development for all people working in the area of ment
health.

Acknowledgment of volunteer work by mental health professionals

By far the most crucial transformation is visible in the medic
community where medical professionals have willingly come to offer training i
mental health issues. They have recognised the need for incorporating knowledg
and information regarding common mental health needs. They recognise th
need to offer community based service. The programme has also bee
instrumental in transforming the attitudes of many private psychiatrists who ar
now working voluntarily in the community. They have made sincere efforts t
ensure that medicines are made available for needy people by pressurisin
government structures, wherever possible.

Sensitising the Community

All these efforts have also led to transformation in the mindsets of peopl
in the government. Beginning with members from the local governmer
(panchayat structures) to primary school teachers or anganwadi workers, the
are now sensitised and come forward to support such families in their ow
villages and communities and cater to their needs. Besides, in many of thes
areas, the police and judiciary are now sensitive to mental illness and are able t
differentiate between a criminal and a person with a mental illness.

From the perspective of BasicNeeds India: Challenges

> "The mental health scene in India at the dawn of the twenty-first century is a bewildering mosaic of immense impoverishment, asymmetrical distribution of scarce resources, islands of relative prosperity intermixed with vast areas of deprivation, conflicting interests and the apparent apathy of governments and the governed alike. In the context of the huge and perhaps unsustainable levels of over-population, the problems appear to be insoluble. Yet a solution must be found if we are to survive. This calls for courage, vision and a vibrant spirit of innovation, unburdened with the obsolescent shibboleths of psychiatric mythology. We will have to get off the beaten track, and embark upon this journey without a road map to help us along. We will have to invent solutions. We have the technical skills required to achieve this goal. Do we have the wisdom to choose the right path?"
>
> **Goel, et al**
> (Ministry of Health and Family Welfare, 2004)

While change is evident, the BasicNeeds India team has encountere
several challenges in the course of the programme. The primary challenge lay
introducing the concept of community mental health, which was perhaps also th

most difficult. While there were several reasons for this, each of them needed to be addressed slowly and systematically.

One of the biggest challenges that this programme faces is the non-availability of skilled professionals at all times. Often, the shortage is so acute the organization has to step in and provide additional funds to get temporary private replacements. In spite of repeated requests to higher governmental authorities, these requests often remain unheard and unattended to for long periods of time. Along with this, other types of non-cooperation by bureaucrats have been instrumental in reducing the pace of growth of the programme.

Associated with this is the factor of non-availability of medical supplies. When drugs are in short supply at their treatment centres, families have to bear the cost of buying them from pharmacies outside, from their meagre resources. The serious implications of discontinuing prescribed medication are often not recognised by the family or even by the field staff. This is a major cause of relapse, and the whole cycle of treatment has to begin all over again.

Another area of concern is the differentiation between common mental illness and severe mental illness. As of today, the widespread understanding of mental illness conjures the stereotypical picture of a deranged person. This is because common mental illness is treated at par with severe mental illness. These perspectives need to be modified for the two to be distinguishable. Accordingly, a treatment plan can be designed that emphasises other therapeutic or counselling methods for common mental illness. This can be included in the training imparted to medical practitioners.

A larger issue requiring attention is the campaign for mental health promotion and ways of doing the same. The focus here is on mental health, not illness. To introduce this awareness early in life, understanding life skills, awareness and education in schools, understanding substance abuse and similar other topics must become a part of the curriculum for self-development. Only when such measures are put in place, and advocated regularly, can people respond with sensitivity, both in the rural and in the urban population. Thus, the role of the government in public health cannot be underestimated. This in turn will also mainstream the mental health programme. But the lack of political and public will is a stumbling block, impeding progress in this direction.

The operational challenges are very many, amongst which the high rate of turnover of trained staff is the most critical factor. When trained personnel leave, it becomes very hard to replace them quickly. Additionally, now that so many of them are already trained in basic issues, future need-based training will have to be designed with better inputs and more rigorously designed programmes.

Another growing challenge is that the programme is expanding at a very fast pace without a corresponding increase in trained staff and infrastructure. Elements like the number of people, the number of villages, areas, camps, and

related activities are growing rapidly. However, the field staff trained ar allocated to them by partner organizations remain the same. Therefore a increase in workload may result in a reduction in the quality of the wo produced. Partners need to work on their future plans, keeping this in mind.

Moving ahead

"We realise that the government cannot do everything. Wherever ther are gaps we appeal to the community to fill them," explains Naidu. *"Communit participation must be there, both in kind and in spirit."*

While an initial breakthrough has been achieved, there is a long way t go. Says Naidu, "We are satisfied with what has been achieved in the limite areas where we started our operations, that we have sensitised the relevan people/bodies, but we are also aware that this is only a start. The quality o healthcare is still a concern. And there are also other issues, such as participatio of women, that need to be addressed."

Chris Underhill, Founder Director and D.M. Naidu, Programme Manager, BN Ind

Assessing its own work BasicNeeds India reports, 'It was observed tha the integration of the Mental Health and Development Programme int mainstream development programmes is a welcome measure. The participatio of volunteers and large sections of the community in the programme has in fac increased self-esteem and confidence levels on the whole. The cooperation fro government departments is encouraging and very positive. Visits to self-hel group meetings confirmed the inclusion of people with mental illness into a groups in an integrated setting. The knowledge of community members ha increased and people are aware about mental illness and its consequences. Th model is holistic, but its application varies from partner to partner based on the

experiences in the development field. However, the liaison with government departments has to be strengthened, and the sustainability factor of the programme needs to be looked into as a long-term goal.'

Global trends in the mental health movement have altered the definition of mental illness in broad social terms. The need for quicker treatment, a greater range of treatment approaches and increased accessibility to treatment facilities have come to light. Many approaches have their place in mental health treatment. At times, a combination of approaches works while at other times, a specific intervention is more effective.

In spite of the new approaches, the psychiatry model continues to be central to the whole process of recovery. The base, especially in developing countries, is still in the institutions of District Hospitals, Primary Health Centres and other such institutional establishments. However, with a huge outlay of Rs. 1000 crores for the District Mental Health Programme in the 11th Five Year Plan in India (2007 –2012), the time is right for a paradigm shift.

Scaling up of the BasicNeeds model of Mental Health and Development can play a significant role in this context. Community resources are central to the process in the BasicNeeds vision and approach. This also implies that the outcome of the interventions for people with mental illness and their families goes well beyond simply recovering or better management of the condition. The crux lies in including persons with mental illness in their own development, part of which demands a stabilization of their own condition.

BasicNeeds India has started efforts to scale up the programme and extend it to other districts in the country. "Over time, we hope to make Mental Health and Development a community movement across the country," says Naidu. "The role of the Alliance, our partners and the community remain critical in this process."

The response lies in laying this foundation through a community based developmental model, whereby components can be utilised to reach goals. The BasicNeeds India experience is an important stepping stone in this process.....

As Shivamma, a woman with mental illness says, "I want to be myself; no dependence on anyone. I want to earn more and save some money so that I can look after my parents in their old age."

A simple desire, but is it a tall order?

BasicNeeds UK

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BasicNeeds India Trust

TRUSTEES (2005-06)

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5.	Ms. Vandana Bedi	*Trustee*
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Annexure

MEMORANDUM OF UNDERSTANDING

Between

Basic Needs India
&
Grameena Abuyadaya Seva Samasthe (GASS)

This document establishes the principles upon which BasicNeeds India and GASS will co-operate to pursue the agreed objectives of working with people with mental illness in development. Both organisations share the belief that the people with mental illness have the right to self-determination in all areas of human development, hence have joined together to support them in their effort for justice and equality.

This Memorandum of Understanding (MoU) describes:

- Introduction
- Description of the partnership
- Values
- The relationship
- The Plan of Action
- Organisational roles
- The budget of GASS
- Resolution of disputes

Introduction

The Community Fund UK has responded to the request from BasicNeeds UK to build an alliance of people with mental illness and their supporters in 3 districts of Southern India. The implementing agency is BasicNeeds India, which in turn will work to carry out the project with its partners. The life cycle of the funding is for 4 years commencing from first April 2004. The first 2 years the funding is 100% of the agreed budgets and from 3rd and 4th years funding will gradually taper. It is expected the partners would in parallel increase their capacity to sustain the initiated project.

Having set out in the preamble the way BasicNeeds India and GASS generally envision their relationship the agreement in this document as being a contract between them for the purpose of achieving the outcome and cross cutting outcomes of the Project. According to need the organisations will act mutually and severally to fulfil the planned work. This first part describes the overall agreement and sets out roles and responsibilities for both BasicNeeds India and GASS. GASS has agreed to implement Mental Health and Development Programme in Dodabalpura taluk in Karnataka.

Description of Partnership

BasicNeeds India and GASS agree to:

- See that the Project is implemented in accordance with BasicNeeds UK
- Ensure transparency in the way the project is managed and the way in which information is made available to all stakeholders
- Develop equality and mutual governance with partners in the way the project is managed over the life of the project
- Compliance with the terms and conditions of the MOU
- MOU is agreed for 4 years, it is subjected to renew every year

Values:

Both the organisations will consciously live the following values:

- The programme ensures inclusion of people with mental illness and caregivers equally without any discrimination to caste, tribe, male, female, adults, youth and old age.
- The most disadvantaged groups and very poor people get top priority.
- Respect for people with mental illness and their potentials.
- People with mental illness have equal opportunities for full participation and exercise their rights.
- Being sensitive to the needs of people with mental illness and responding in a realistic manner.
- Open discussions about the issues and problems of such people whilst maintaining confidentiality.
- Involvement of the larger community and local resources in taking further the cause.
- Maintain transparency, accountability, and mutual trust.

Relationship

The five modules namely Community Mental Health, Capacity Building, Income Generation, Administration and Action Research agreed upon more clearly explained in Annexure 1 defines the relationship.

Plan of Action

Annexure 2 describing the proposal and scheduled activities for year 1 become part and parcel of this MoU for monitoring and evaluation. The project outcome and cross-cutting outcomes, and the indicators govern the schedule of activities.

Organisational roles

The geographical locations and differing resources available to BasicNeeds India and GASS will mean that each organisation will take differing roles, provide different resources and skills in the implementation of the project. This will ensure that the required skill mix for the project is achieved.

Contribution of BasicNeeds India

Contributions to be made by BasicNeeds India will be:

a) To set up local partner implementation and manage local partner work through partnership MOUs.
b) To provide technical support and training to the local partners, as set out in the project design, in the following areas:
- Capacity building (to include consultation processes)
- Community Mental Health
- Sustainable livelihoods
- Research and Policy work
- Administration (to include monitoring, review and evaluation processes as well finance and reporting procedures)

c) To lead the formation of an Alliance of NGOs supporting change in mental health and the development and implementation of government mental health policies.
d) To ensure that BasicNeeds India partners provide the required monitoring data, financial information and reports according to the agreed monitoring system timetable and requirements.
e) To review quarterly the performance of GASS and to release funds every quarterly as agreed.

Contribution of GASS

a) Implementing the project as agreed and more described in the annexure.
b) Sending quarterly reports on time in the required formats.
c) Cooperate and collaborate with BasicNeeds India in capacity building with mentally ill people, families and larger communities.
d) Seeking prior approval for any change in programme or budget if required.
f) To play an active role in the promotion of community mental health and development and to build an alliance at the State level by the end of the project period.

Budget

Both the parties have agreed to work in partnership for 4 years, and the budget for 1st year is amounting to Rs. xxxx for a period April 2004 - March 2005

GASS undertakes to carry out the plan of action respecting the values.

BasicNeeds India undertakes to provide agreed funds in four instalments every quarterly. Proper receipts need to be sent to BasicNeeds India.

Quarterly reports comprising of updated qualitative and quantitative information and statement of accounts need to be submitted to BasicNeeds India on or before 10th of the first month of each quarter (the first quarter begins from 1st April and the first quarterly report is expected by 10th July)

A separate account needs to be maintained for this purpose and these accounts are subject to auditing.

Resolution of disputes

If a dispute arises between BasicNeeds India and GASS it will be referred in the first instance to the BasicNeeds India Programme Manager to resolve. If the dispute cannot be resolved within a month it will be referred to the BasicNeeds India Trust. The Trust will consult the necessary parties in the event the dispute warrants such attention.

Amali
Secretary
GASS

D. M. Naidu
Secretary
BasicNeeds India

Annexure 1

BasicNeeds in participation with persons with mental illness, their carers\families and CBOs evolved a model comprising of five modules.

1. Community Mental Health

The purpose of Community Mental Health Care is to assist the individual with mental illness to obtain an adequate level of functioning, to enable them participate in a sustainable self-reliant programme leading them to exert the human potentials within their own communities. The staff of the CBOs will be trained in identifying persons with mental health problems and designing a need based care programme and follow up. Training will be provided by the staff of BasicNeeds and external resource persons and organisations. In particular, the services of the Community Mental Health Unit at NIMHANS will be used for training of the CBO staff.

2. Capacity Building and Animation

As BasicNeeds works as a catalyst through CBOs, it is important to build the capacities of the local organisations so that they would be able to independently manage the community mental health and development programme. The project holders and the staff will be trained on an ongoing basis, the training will equip them with the skills to manage all the capacity building elements of the programme. In particular the focus of this community development work will be mentally ill people themselves and their carers affording them opportunities to come together at regular intervals to talk about relevant issues and to assist them in developing appropriate strategies in sustainable livelihoods. Capacity building will equip them with the knowledge about the illness and the coping mechanism. Ultimately the stigma attached to people with mental illness fades and they have a rightful place in their community.

3. Income Generation

Poverty is a consequence and cause of mental illness, therefore one of the touchstones of the philosophy is to involve people with mental illness and family members in economically viable activities. Using a group animation approach, mentally ill people will be encouraged to find practical solutions to the problems that they themselves have identified. Economic development programmes appropriate to the individual or his family members will be designed. The CBOs will also be trained in identifying local resources and trades and in identifying the capabilities and making appropriate referrals. Savings and credit groups comprising people with mental illness and their carers will be formed and appropriate links will be made to micro finance organisations and to locally-based schemes run by the Government for disadvantaged people.

4. Research

Action research will be developed along with people who have experience of mental illness to understand their lives in the community. The CBOs will

document their learnings, experiences and impact and disseminate this information to other interested organisations and individuals. The end product of research is attaining knowledge leading to change in the lifestyles of people with mental illness.

5. Administration

The programmes will be reviewed through meetings and field visits. Individual case records and activities will be documented for monitoring and evaluation. Programme and financial reports will also be submitted periodically.

During the year, you are expected to meet the needs of 225+60 people with mental illness in Dodabalapura Taluk.

Main outcome

1. 273 mentally ill women and 273 mentally ill men will benefit from Community Mental Health and Development Programme by March 2007. 191 men and 191 women have their condition stabilised (including prevention of relapse or, where possible, recovery) through the implementation of a Community Mental Health and Development model in Doddabalpura taluk of Karnataka state.	1. Number of mentally ill men and women who have had their condition stabilised or who have recovered* Plus indicator of community-based nature of interventions, such as: 2. Number of mentally ill people supported to sustain treatment and provided with follow-up within the community, by families/CBOs, self-help groups*/** and community-based health care services.

Notes

* Measured through individual programme records of mentally ill people, including details of their diagnosis and professional follow-up. Confirmed by interviews with mentally ill people and their families and annual review processes.

** Measured from partner NGO records and reports and confirmed by interviews with families, self-help groups and CBO staff.

Annexure 2

GASS annual plan for April 2004 - March 2005	

Activities for year 1	**Total**	**Qtr 1** Apr-Jun 04	**Qtr 2** Jul-Sep 04	**Qtr 3** Oct-Dec 04	**Qtr 4** Jan-Mar 05
25 staff of the organization will be trained and implementing the community mental health and development model	4	1	1	1	1
60 new people with mental illness which include 30 men and 30 women with mental illness + another 225 people already working	225+ 60	15	15	15	15
Diagnosis and treatment avalibale to identified people with MI in the catchment area of partners	285	240	255	270	285
10% of people with mental illness are stabilised wit h equal representation from men and women					
Networking with professionals, resource organizations and research institute and develop resource directory					
Celebration of world mental health day	1	0	0	1	0
Consultation with mentally ill men and women and their families conducted in one district and this influences the detailed design of the project	3	0	1	2	0
Baseline documents are produced in the one district	1	first draft	final draft	0	0
Integration of people with mental illness in to the existing self help groups					
Recording of the individual case records	285	all	all	all	all
Documentation of 2 life stories	2	1	0	1	0

37 people with mental illness will be engaged in income-generation activities	37	9	9	9	10	
Identification of suitable work placement						
30 community group training for 900 (30*30) people which include, caregivers meetings, training programmes for anaganwadi teachers health workers, panchyath members and etc	30	7	8	8	7	
4 capacity building training programme for 25 people (25*4)	4	1	1	1	1	
4 days of Training on mental health to partners	4	1	1	1	1	
4 training programme for research and documentation for 25 people (4*25)	4	1	1	1	1	
12 street theatres	12	2	4	3	3	
Development of posters, materials on mental health (200 posters)	200				200	
Training volunteers to create a cadre of barefoot counsellors (numbers to be agreed up on)						
4 Review meetings	4	1	1	1	1	
1 Annual evaluation	1	0	0	0	1	
Mass Meetings	4	1	1	1	1	
Vocational training for the people	6	1	1	2	2	

Already we are working with 225 people with mental illness

Acronyms

CBO	Community Based Organisation
CBR	Community Based Rehabilitation
NGO	Non-governmental Organisation
PHC	Primary Health Centre
SHG	Self-help Group

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BasicRights

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